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**A qualitative study of factors which influence help seeking by women who develop pre-eclampsia and the response of health care workers.**

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**A Qualitative Study of Factors  
which Influence Help Seeking  
by Women who Develop  
Pre-eclampsia  
and the Response of Health Care Workers**

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A dissertation presented for the Degree of Doctor of Philosophy,  
King's College London,  
Florence Nightingale Faculty of Nursing and Midwifery  
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# **Abstract**

## **Background**

Pre-eclampsia is a disorder of pregnancy, where delay in diagnosis and management of warning signs can lead to serious morbidity and mortality for women and their infants.

## **Aim**

The aim of this study was to understand factors that influenced women's help seeking about early warning signs and symptoms, and health care workers' response to women's concerns.

## **Design and Methods**

Candidacy theory and street level bureaucracy (SLB) informed the analytical approach to the study.

The principles of a narrative approach were used to explore the experiences of 23 women who had pre-eclampsia, 5 family members, 17 health care workers, and 5 representatives of service user groups. Purposive heterogeneity sampling was used to select participants.

## **Findings**

Themes associated with help-seeking among women and families included: level of knowledge and understanding, perception of signs and symptoms, self-monitoring, making trade-offs and organisational constraints. All women classed as low risk at pregnancy booking were unhappy about the lack of information they were offered on pre-eclampsia. Women classified as high risk women often felt they had too much information. Candidacy theory illuminated how women negotiated their care using knowledge, previous experience and self-monitoring.

Themes identified from health care workers included; information sharing, difficulty of diagnosing pre-eclampsia, responsibility and self-monitoring, clinical need versus clinical availability, and relationships and continuity of care. Individualised care was often compromised as frontline healthcare providers made choices while struggling to meet both the organisation and the individual service user needs, which resonates with Street level bureaucracy theory.

## **Conclusion and implications for practice, policy and future research**

Women and their families need individualised information on signs and symptoms of pre-eclampsia to facilitate help seeking for which healthcare workers need additional training.

Not all women experience signs and symptoms of pre-eclampsia, highlighting the importance of regular antenatal appointments and the importance of telling women

why their blood pressure is monitored. Women often used self-monitoring and this needs further research.

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# Contents

Abstract.....	2
Acknowledgements.....	4
Contents .....	6
Table of tables .....	10
Table of figures .....	10
Glossary of Terms and Abbreviations .....	11
Chapter 1 Introduction .....	13
1.1 Pre-eclampsia: definition and consequences .....	13
1.2 Promoting safety in the maternity services through engaging women and families .....	17
1.3 Help-seeking and ‘speaking up’.....	19
1.4 Theoretical approaches .....	20
1.5 Summary .....	20
1.6 Study design.....	21
1.7 Structure of the thesis.....	21
1.8 Writing style .....	23
Chapter 2 Background .....	24
2.1 Difficulties in defining quality and safety in healthcare .....	24
2.2 Policies, enquiries and reports on quality and safety of healthcare .....	25
2.3 Policies, enquiries and reports on quality and safety of maternity care .....	28
2.4 Summary .....	35
Chapter 3: Approaches to understanding help- seeking and provider responses..	37
3.1 Symptom Perception Theory .....	37
3.2 Candidacy Theory .....	42
3.3 Street-level Bureaucracy Theory .....	46

3.4 Summary .....	52
Chapter 4: Experiences of help-seeking by women with early warning signs of pre-eclampsia and their families, and the organisational response .....	53
4.1 Systematic review and narrative synthesis .....	53
4.2 Search and selection strategy .....	55
4.3 Quality appraisal.....	56
4.4 Findings.....	57
4.5 Data extraction and synthesis .....	58
4.6 Narrative synthesis.....	68
4.7 Discussion and implications of findings .....	77
4.8 Limitations of the synthesis .....	80
4.9 Conclusion.....	81
Chapter 5 Research Design and Methodology .....	83
5.1 Context, origins and development of the PhD project .....	84
5.2 Rationale for methodological approach .....	85
5.3 Ontological and epistemological approach .....	88
5.4 Study rigour .....	89
5.5 Methods.....	91
5.6 Interviews with women and partners/family members .....	94
5.7 Interviews with healthcare workers.....	102
5.8 Interviews with charity group representatives.....	106
5.9 Analysis .....	110
5.10 Research governance and ethics .....	112
5.11 Reflexivity .....	114
5.12 Summary .....	115



Chapter 6: Factors affecting help-seeking of women and families .....	117
6.1 Introduction.....	117
6.2 Participant Characteristics.....	117
6.3 Brief overview: Themes and subthemes .....	118
6.4 Theme 1: Knowledge and understanding .....	119
6.5 Theme 2: Sign and symptom perception .....	125
6.6 Theme 3: Self-monitoring .....	132
6.7 Theme 4: Trade-offs .....	137
6.8 Theme 5: Organisational constraints .....	141
6.9 Application of findings to Candidacy Theory.....	151
6.10 Summary .....	154
Chapter 7: Factors affecting healthcare workers' responses .....	156
7.1 Introduction.....	156
7.2 Participant characteristics.....	156
7.3 Brief overview: Themes and subthemes .....	157
7.4 Theme 1: Information sharing.....	157
7.5 Theme 2: Differentiating signs and symptoms.....	163
7.6 Theme 3: Responsibility and self-monitoring.....	167
7.7 Theme 4: Clinical need versus clinical availability .....	169
7.8 Theme 5: Care coordination .....	177
7.9 Summary .....	181
Chapter 8: Discussion and conclusions .....	182
8.1 Overview of aims and objectives .....	182
8.2 Candidacy Theory .....	184
8.3 Street-level Bureaucracy (SLB) .....	197

8.4 Conclusion.....	203
8.5 Strengths and limitations of the study.....	204
8.6 Conclusions and implications for clinical practice, policy and further research .....	206
9.0 References.....	210
10. Appendices .....	246
Appendix1 BMC pregnancy and Birth Published Article .....	246
Appendix 2 Search Strategy for Narrative Synthesis.....	262
Appendix 3 Women and family interview topic guidelines .....	263
Appendix 4 Health care worker interview topic guidelines.....	265
Appendix 5 PPI interview template.....	267
Appendix 6 Summary of stories.....	270
Appendix 7 Research Protocol .....	273
Appendix 8 REC letter .....	318
Appendix 9 Women and families information leaflet.....	323
Appendix 10 Health Care Workers information leaflet.....	327
Appendix 11 Information Leaflet for PPI.....	331
Appendix 12 Participant Consent form .....	335
Appendix 13 Dissemination .....	337

## Table of tables

Table 1 Negotiating the candidacy journey for health services - an exploration from Dixon-Woods et al. 2006.....	43
Table 2 SPICE Framework Search Terms.....	54
Table 3 Characteristic of included studies .....	59
Table 4 Summary table of themes and sub themes.....	677
Table 5 Priori Sampling Framework for women.....	96
Table 6 Demographic characteristics of women interviewed.....	99
Table 7 Demographic characteristics of family members interviewed.....	100
Table 8 Priori Sampling Framework for health care workers.....	104
Table 9 Demographic characteristics of healthcare workers interviewed.....	106
Table 10 Factors affecting help-seeking from women's, their partners' and families' perspectives; Themes and sub-themes .....	11919
Table 11 Stages of candidacy, facilitators and barriers to help-seeking and response .....	152
Table 12 Theme and subthemes identified from healthcare worker and charity group interviews.....	157

## Table of figures

Figure 1 Moller-Leimkuhler, 2002 Model of symptom perception (adapted and modified from Gijsbers van Wijk and Kolk, 1997).....	388
Figure 2 to show flow of articles selected .....	577

## Glossary of Terms and Abbreviations

APEC	Action on Pre-eclampsia
BMI	Body Mass Index
BTA	Birth Trauma Association
CEMACH	Confidential Enquiry into Maternal and Child Health
CQC	Care Quality Commission
CMACE	Centre for Maternal and Child Enquiries
CSM	Common Sense Model of Self-Regulation
EC	European Commission
ESRC	Economic and Social Research Council
FFT	Friends and Families Test
HELLP	Haemolysis, Elevated Liver enzymes and Low Platelet count
ICF	Informed Consent Form
IOM	Institute of Medicine
JLA	James Lind Alliance
Main REC	Main Research Ethics Committee
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries
MSLC	Maternity Service Liaison Committee
NHS R&D	National Health Service Research & Development
NICE	National Institute for Health and Care Excellence
NCT	National Childbirth Trust
NMC	Nursing and Midwifery Council
NPEU	National Perinatal Epidemiology Unit
NPSA	National Patient Safety Agency
OSOP	One Sheet of Paper
PI	Principal Investigator
PICO	Patient problem, Intervention, Comparison and Outcome
PPI	Public and Patient Involvement
PRECOG	Pre-eclampsia community guideline

Participant	An individual who takes part in a clinical trial
RCM	Royal College of Midwives
REC	Research Ethics Committee
RCOG	Royal College of Obstetricians and Gynaecologists
Sands	Stillbirth and Neonatal Death charity
SGA	Small for gestational age
SLB	Street-Level Bureaucracy
SPICE	Setting, Perspective, Intervention, Comparison, Evaluation
WHO	World Health Organization
UK	United Kingdom
USA	United States of America

# Chapter 1 Introduction

The study presented in this thesis explores the potential of pregnant and postpartum women, their partners or other family members, to raise concerns regarding the early onset of pre-eclampsia, and what prompted an effective response from the healthcare workers to whom they reported their concerns. The study aimed to improve outcomes for women with pre-eclampsia and their infants, by understanding the potential for women to identify early warning signs of pre-eclampsia and seek help to improve their chances of a timely and appropriate response from healthcare workers.

This chapter will define pre-eclampsia, its prevalence and potential consequences if untreated. The rationale for exploring women's involvement with escalation of their health concerns will be briefly discussed by considering the different bodies of literature exploring 'patient involvement in their own safety' and help-seeking within organisational contexts. A more in-depth discussion will be presented in Chapters 2, 3 and 4. A brief outline of the aims, objectives and methodology of this PhD thesis, and an indication of the contents of subsequent chapters, are given below.

## 1.1 Pre-eclampsia: definition and consequences

Pre-eclampsia is a major pregnancy complication and a leading global cause of maternal and perinatal mortality and morbidity (Steeegers et al., 2010). It is a pregnancy-specific disease characterised by de novo development of concurrent hypertension and proteinuria, sometimes progressing into a multisystem disorder (Steeegers et al., 2010). The potential adverse perinatal outcomes include intrauterine growth restriction, preterm birth and fetal death (Tuuli et al., 2011). If untreated, pre-eclampsia can develop into eclampsia, a convulsive condition when maternal seizures develop (Williams and Craft, 2012; NICE, 2011). Severe pre-eclampsia is pre-eclampsia with one or a combination of severe hypertension, biochemical impairment or haematological impairment. HELLP syndrome

(Haemolysis, Elevated Liver enzymes and Low Platelet count) is regarded as a variant of severe pre-eclampsia and can occur in 10 to 20 percent of cases with severe pre-eclampsia (Haram et al., 2009). For the sake of brevity, in the remainder of this thesis pre-eclampsia should be understood to include severe pre-eclampsia and eclampsia unless otherwise indicated. For the purposes of this thesis, pre-eclampsia is defined as “a combination of a new hypertension and proteinuria and typically occurs after 20 weeks’ gestation” (NICE, 2011).

The incidence of pre-eclampsia and eclampsia varies internationally. It contributes to 15 percent of preterm births and between 9 and 26 percent of maternal deaths worldwide (Townsend et al., 2016). In the United Kingdom (UK) the proportion of maternal deaths from hypertensive disorders is around 2 to 8 percent (Knight et al., 2016). This contrasts with rates in low income countries where eclampsia is more common (Duley, 2009). In Latin America and the Caribbean, hypertensive disorders are responsible for around 26 percent of maternal deaths, whereas in Africa and Asia they contribute to around 9 percent of deaths (Steegers et al., 2010). Reasons why rates of maternal deaths due to hypertensive disorders are higher in low-income countries could be attributable to inadequate access to healthcare for poorer women. This is especially true for regions with low numbers of skilled health workers, such as sub-Saharan Africa and South Asia. Other factors identified by the World Health Organization (WHO) that prevent women from receiving or seeking care during pregnancy and childbirth include poverty, distance to a healthcare facility, lack of information, inadequate services and cultural practices (WHO, 2016). Interestingly, the incidence of pre-eclampsia is reported to have increased in the United States of America (USA) and was recently estimated at around 7 percent (Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, 2016). This may be related to an increased prevalence of predisposing factors such as chronic hypertension, diabetes and obesity, and lack of access to care among poor women (Berg et al., 2009).

Management of pre-eclampsia involves identifying women developing pre-eclampsia and preventing complications by inducing delivery when necessary (Verghese et al., 2012). In the UK it is recommended that pre-eclampsia is routinely screened for at the booking appointment, which is when women enter the maternity pathway, and at each pregnancy contact, where blood pressure measurement and urinalysis for protein should be undertaken (NICE, 2017). Failure to identify and act on risk factors at booking and to monitor and intervene appropriately from 20 weeks' gestation contributes to a significant proportion of pre-eclampsia related maternal and fetal deaths (Verghese et al., 2012) .

The UK NICE 2010 antenatal care guidelines also recommend that pregnant women are risk-assessed for pre-eclampsia at booking (NICE 2010). (NICE, or the National Institute for Health and Care Excellence, is a public body which provides national guidance and advice to improve health and social care.) The aim of risk assessment in pregnancy is to decrease perinatal and maternal mortality by identifying those women at risk of an adverse outcome and referring them to the appropriate treatment (Stahl and Hundley, 2003). Women are categorised as having an increased risk of pre-eclampsia if they have one high-risk factor, or more than one moderate risk factor for pre-eclampsia as defined by NICE (2013). High-risk factors include: hypertensive disease in a previous pregnancy, chronic kidney disease, autoimmune disease, type 1 or type 2 diabetes, and chronic hypertension. Moderate-risk factors include: first pregnancy, age 40 years or older, pregnancy interval of more than 10 years, body mass index (BMI) of 35 kg/m<sup>2</sup> or more at first visit, family history of pre-eclampsia and multiple pregnancy (NICE, 2016).

Verghese et al. (2012) found that the NICE guidelines on antenatal screening for pre-eclampsia were moderately sensitive, detecting nearly 80 percent of potential cases at booking. They analysed information from antenatal records and direct patient interviews in one inner-city hospital to assess the screening performance of the guidelines using estimates of sensitivity, specificity and positive and negative predictive values (Verghese et al., 2012). The specificity was found to be only 54 percent (Verghese et al., 2012). They did not ask women about signs and



symptoms. These poor results suggest that other strategies may also be needed to predict the risk of pre-eclampsia developing so that early interventions can occur.

One approach could be to explore if women and relevant family members are aware of early signs of health deterioration before healthcare workers or routine monitoring systems have identified any problems. Early warning symptoms and signs of onset of severe pre-eclampsia which can result in a woman's health deteriorating very quickly, include specific physical symptoms such as severe headaches that do not resolve with simple painkillers, problems with vision such as blurring or flashing before the eyes, severe pain just below the ribs, heartburn that does not resolve with antacids, rapidly increasing swelling of the face, hands or feet, and feeling very unwell (RCOG, 2012).

Current NICE and RCOG (Royal College of Obstetricians and Gynaecologists) guidance emphasise the importance of providing information for women on signs and symptoms of pre-eclampsia, encouraging women to seek professional help if they experience any of these (NICE, 2016; RCOG, 2012). For example, NICE guidance for women with hypertensive disorders suggests that “...*pregnant women should be made aware of the need to seek immediate advice from a healthcare professional if they experience symptoms of pre-eclampsia.*” However, there is limited evidence as to whether this guidance is effective i.e. if women are aware of the signs and symptoms of pre-eclampsia or other factors which may affect their identifying signs and symptoms of pre-eclampsia and help-seeking. Very little attention has been paid to the interaction with healthcare workers when women do report any of these signs and symptoms. The systematic review and narrative synthesis in Chapter 4 examines the extent to which the available literature could inform a greater understanding of the experiences of women and their families who raised an early warning about potential symptoms and signs of pre-eclampsia, and the organisational response. The review identified that women may not know about signs and symptoms of pre-eclampsia (Carter et al., 2017; Gudu, 2017; Leeners et al., 2006; Sauv   et al., 2008; You et al., 2012; Brewer et al., 2015; Kidner, 2004; De Souza et al., 2007). A key finding was that there was limited qualitative

research available which explores how healthcare professionals' responses affected women's help-seeking with pre-eclampsia.

Different bodies of literature have explored how complex help-seeking and 'patient involvement in their own safety' operate within organisational contexts. These will be discussed below: first, by defining patient safety and what components contribute to quality care within an organisational context; and second, by exploring how the quality of care provided may affect women and their families' ability to seek help, and healthcare workers' ability to respond.

## **1.2 Promoting safety in the maternity services through engaging women and families**

Pregnancy and childbirth have traditionally been seen as normal physiological processes with high expectations of a healthy outcome for the mother and baby in the UK. Safe care in maternity services should mean the reliable reduction of risk of harm to mother and baby during pregnancy, childbirth and the postpartum period (King's Fund, 2008). If women or their babies do become unwell the transition from routine to emergency care can occur rapidly and unexpectedly (King's Fund 2008). By engaging women and their families in their own safety it is possible outcomes could be improved.

Patient involvement in the safety of their own care is an emerging field in general healthcare in the UK, but has been recognised as a priority including government-led health reviews and reports following a series of high profile health enquiries into poor outcomes of NHS care (Department of Health (DH), 2000; DH, 2013a; Francis, 2013). The World Health Organization (WHO) recognises that patients and carers are at the very centre of the quest to improve healthcare safety (WHO, 2005), and the Council of Europe and WHO's World Alliance for Patient Safety have recommended that patients should be involved in the reporting of incidents and safety management of their own care (Perneger, 2008; WHO, 2008).

Safety can be defined as: “...where a culture is created which supports good outcomes and avoids injury to patients/service users” (IOM, 2001). Thus patient safety with respect to prevention of serious health outcomes has been defined in two important ways, one looking at the prevention of harm, and the other looking more broadly at the components of quality care. An example of prevention of harm is “the avoidance, prevention and amelioration of adverse outcomes or injuries stemming from the process of healthcare” (Vincent, 2010). Safety was explored under the definition of quality in the Institute of Medicine’s (IOM) report ‘Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century’, as being “safe, efficient, effective, equitable, patient-centred and timely” (2001).

The research presented in this thesis will refer to both definitions where the quality of care delivered may affect women and their families’ ability to seek help and the healthcare workers’ ability to respond.

By exploring the domains of safe care as defined above, it is possible that aspects of help-seeking could be affected. For example, when exploring efficiency, which has been defined as “the avoidance of waste, including overuse and waste of equipment, supplies, ideas and energy” (IOM, 2001), it could be that responses to women help-seeking with pre-eclampsia could be affected by the resources - healthcare workers and their skills mix, hospital beds or equipment - that are available. Similarly, their experiences and outcomes could be affected by the timeliness of treatment. Timeliness can be defined as where waits and harmful delays are reduced for both patients and care providers (Berwick, 2002). WHO recognises that the majority of deaths related to pre-eclampsia and eclampsia could be avoided if women received timely and effective care, delivered according to evidence-based standards (2014).

In general healthcare and in maternity care there is growing evidence that patients and their families do not feel listened to if they have concerns about signs and symptoms that can have a life-threatening impact. As a consequence, their health may deteriorate if an appropriate, timely response from healthcare professionals is not initiated (Redshaw et al., 2014; CQC, 2013; Francis, 2013; Rance et al., 2013).

Over the years, findings from previously published enquiries such as the triennial Confidential Enquiry into Maternal and Child Health (CEMACH), the Francis Inquiry (2013) and the Berwick Report (2013) have identified a range of safety issues including the domains defined above, impacting on maternal outcomes including failure to listen and respond to women with deteriorating health (CMACE, 2011; NPSA, 2007b; Lewis et al., 2001). These reports and enquiries will be discussed in further detail in Chapter 2.

### **1.3 Help-seeking and ‘speaking up’**

The research presented in this thesis focuses on the aspect of women’s involvement in their own care, specifically with help-seeking and ‘speaking up’ about a health deterioration.

‘Speaking up’ was an unexpected finding in a qualitative organisational case study of 2010 undertaken as part of the Birthplace in England Research Programme (Rance et al., 2013), which looked at perinatal and maternal outcomes by planned place of birth for healthy women with low-risk pregnancies. In the study, *‘speaking up’ was defined “as insistent and vehement communication when faced with failure by staff to listen and respond”* (Rance et al., 2013). The research also highlighted that ‘speaking up’ was no guarantee of being listened to, or having an appropriate response from a healthcare professional. Examples of staff failure to listen and respond included: ignoring requests or dismissing safety alerts; delaying or withholding information, care or support; disbelieving the woman’s account, responding brusquely, refusing labouring women admission or sending them home feeling unsafe; and refusing the presence of midwife to attend a planned homebirth (Rance et al., 2013). The research focus was not specifically about pre-eclampsia but identified factors in maternity that could affect help-seeking in general e.g. the role of the relatives and healthcare workers.

## 1.4 Theoretical approaches

To explore the complexity of help-seeking help for a deterioration in health, theoretical approaches were needed to question and extend existing literature.

The two main theoretical frameworks of help-seeking selected for this thesis were:

- Candidacy Theory, which was used to inform the exploration of how women and their families negotiated access to healthcare with signs and symptoms of pre-eclampsia (Dixon- Woods et al., 2006; Dixon-Woods et al., 2005).
- Lipsky's concept of Street Level Bureaucracy, which was used as a lens to explore contextual and organisational factors affecting the healthcare workers' response (Lipsky, 2010).

Neither of these theories and frameworks has previously been used to explore speaking up or help-seeking for women with pre-eclampsia or healthcare workers' response, so this is an important new contribution to the field. The Symptom Perception Theory (Moller-Leimkuhler, 2002; Gijsbers Van Wijk and Kolk, 1997) was used in conjunction to the two theories above, to understand factors affecting help seeking with sign and symptom perception of pre-eclampsia. (See chapters 3 4, 6, 7 and 8).

## 1.5 Summary

The introduction illustrates that although current guidance provides information for women on how to identify signs and symptoms of the onset of pre-eclampsia and the need to seek professional help, limited research had been undertaken on factors which affect women help-seeking or speaking up with signs and symptoms of pre-eclampsia or on what affects healthcare workers' responses.

This study therefore aimed to use a qualitative approach to contribute to women's health through understanding the factors that affect women speaking up with signs and symptoms of pre-eclampsia, and the interaction with healthcare workers when

they try to do this. A brief examination of the study design is provided below. Chapter 5 presents the methodology in depth.

## **1.6 Study design**

The empirical research utilised a qualitative approach to enable an understanding of the phenomenon (Green & Thorogood, 2009). The study explored the experiences of women, their partners or other relatives, healthcare workers and representatives of charity groups, using narrative interviews with a semi-structured component. The charity groups included: Action on Pre-eclampsia (APEC), Maternity Service Liaison Committees (MSLC), National Childbirth Trust (NCT), Birth Trauma Association (BTA) and MAMA Academy. Purposive heterogeneity sampling was used to select participants. Primary data were stored and managed using NVivo 10 software. Thematic analysis was used to identify codes and themes.

This study aims to provide an important insight to understand current social and organisational factors that affect women, their partners and families and lead them to seek help about signs and symptoms indicating deteriorating health as a result of the onset of pre-eclampsia.

It also aims to improve understanding as to how health workers can be facilitated to listen and respond appropriately so that improvements to the safety and quality of care can be made in the future, and to highlight where further research is needed

## **1.7 Structure of the thesis**

Chapter 2 will provide an overview of how patients, their partners and other relatives have been involved in patient safety initiatives relevant to safety in NHS maternity care in England.

Chapter 3 will explore different approaches to help-seeking to understand what factors may affect women and their families help-seeking with pre-eclampsia, and

the provider response. Approaches will include Symptom Perception Theory, Candidacy Theory and the Street-level Bureaucracy Theory.

Chapter 4 is a systematic review and narrative synthesis which aims to create a greater understanding of the factors that influence women and their families raising early warnings about potential signs and symptoms of pre-eclampsia within an organisational context.

Chapter 5 will describe and justify the methods used for the study, including an explanation of the iterative and qualitative methods used and an explanation of the narrative approach.

Chapter 6 will present factors affecting help-seeking from the perspectives of women and their families; the aim of the chapter was to explore the original objective to identify the range of health concerns raised by women and their partners and families that are associated with signs and symptoms of pre-eclampsia or eclampsia during pregnancy, labour or the postnatal period, and that require urgent medical attention.

Chapter 7 will present factors affecting healthcare workers responding to women with signs and symptoms of pre-eclampsia from the perspectives of healthcare workers and charity representatives. The aims of this chapter was therefore to answer the third objective of the study, which was to identify organisational, professional and social factors that influence health workers' ability to respond to the health concerns raised by women and their families.

Chapter 8 is a discussion and conclusion chapter which will link theories and research to further analyse the themes and subthemes identified in Chapters 6 and 7, to create greater understanding and add to what is currently known. It will also aim to develop an understanding of the implications of the findings for policy and practice to improve quality and safety of care, and to identify future research priorities.

## **1.8 Writing style**

The third-person narrative is used throughout the thesis with the exception of Chapter 5 Research Design Methodology, where I have used a first-person narrative to demonstrate my understanding of reflexivity and the roles I have had as both a researcher and as a midwife which may have influenced the research process.



## Chapter 2 Background

This purpose of this chapter is to consider policies, enquiries, guidelines and reports, first in general healthcare and second in maternity care, to provide a context regarding the circumstances in which women and their families may want to raise health concerns and the problems they may experience having these responded to.

### 2.1 Difficulties in defining quality and safety in healthcare

Patient safety with respect to prevention of serious health outcomes was briefly defined in two ways in Chapter 1, first as considering the prevention of harm, and second, as encompassing more broadly the components of quality healthcare. Due to the complexity of the topic there are many definitions of quality and safety in healthcare. Most recognise that quality of care is an integral part of patient safety for example in the United Kingdom (UK) quality is defined as having three dimensions: safety, effectiveness and patient centeredness (Department of Health (DH), 2008). A similar but more comprehensive definition is based on the Institute of Medicine's (IOM) report 'Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century', which defines quality care as "*safe, efficient, effective, equitable, patient-centred and timely*" (2001). The World Health Organization (WHO) uses similar dimensions to the IOM, namely "*effective, efficient, accessible, timely, acceptable, evidence-based, equitable, safe and client centred*" (WHO, 2006).

It can be seen from the above definitions that quality and safety of care are closely intertwined and that the components of quality care impact upon safety. However, Vincent (2010) in his book *Patient Safety* defines patient safety separately as "*the avoidance, prevention and amelioration of adverse outcomes or injuries stemming from the process of healthcare*". He recognises the importance of the amelioration of harm in healthcare and refers to the need for rapid medical intervention when there is an immediate crisis, and also the need to care for injured patients and to support the staff involved (Vincent et al., 2013). In line with the above IOM and WHO definitions he acknowledges that safety can be seen as one aspect of the

broader concerns of quality of care, and he separates the two by defining quality as addressing the intended results of the healthcare system and safety as being concerned with the many ways in which a system can fail to function (Vincent et al., 2013).

In the UK there has been recognition that healthcare can cause harm, with a number of high-profile health inquiries and government health reviews and reports into failings in NHS healthcare (Francis, 2013; DH, 2013a); these will be discussed in greater detail below, first in general healthcare and then in maternity care with relevance to help-seeking or speaking up.

## **2.2 Policies, enquiries and reports on quality and safety of healthcare**

The importance of quality and safety of care in reducing harm has been recognised in the UK in recent policy changes following a number of high-profile health inquiries and recent government health reviews and reports into failings in NHS healthcare (Francis, 2013; DH, 2013a). Regrettably such reports and reviews are nothing new, and are preceded by the report 'An Organisation with a Memory' (DH, 2000) which followed the Bristol Inquiry into paediatric cardiac surgery at the city's Royal Infirmary from 1984-1995 (DH, 2001b). A primary recommendation of this report was that patients and the public should be involved in decisions about their care and that a mandatory reporting system for adverse health events and specified near-misses should be set up.

The report led to the development in 2001 of the National Patient Safety Agency (NPSA), whose aim is to reduce risks to patients receiving NHS care and to improve safety. The NPSA identified five levels of harm resulting from patient safety incidents: no harm, low, moderate or severe harm, and death. It established the National Reporting and Learning System (NRLS), a voluntary scheme to monitor adverse healthcare, in 2003 (NPSA, 2014). In 2004 NPSA identified seven steps to patient safety: to build a safety culture; to lead and support your staff; to integrate your risk management strategy; to promote reporting, involve and

communicate with patients and the public; to learn and share safety lessons; and to implement solutions to prevent harm (NPSA, 2004). In these reports there was little recognition of how patients could be involved in their own safety generally, with minimal mention of their involvement when their health deteriorated.

Significant for this PhD research, as a result of data collected by the NRLS in 2007, two reports specifically identified the importance of recognising and responding to early signs of deterioration of patient health (NPSA, 2007a; NPSA, 2007b). The National Institute for Health and Care Excellence (NICE) published guidelines specifically regarding acute deterioration of health in adult in-patients and the healthcare response needed (2007). Although these reports and guidelines highlighted the social and organisational complexity of responding to a patient with deteriorating health, they did not specifically identify how patients could be involved in their own safety or have their voices heard when escalation of care was required. The original NPSA was replaced twice, once in June 2012 with the NHS Commissioning Board Special Health Authority (the Board Authority) and the National Reporting and Learning System (NRLS), and more recently in April 2016 with NHS Improvement (NHS Improvement, 2016).

The importance of involving patients in safety was also part of 'Health Reform in England', which aimed to develop a patient-led National Health Service (NHS) that used resources as effectively and fairly as possible to promote health, reduce health inequalities and deliver the best and safest healthcare (DH, 2006a). The document 'Safety first' recommended that patients and carers were enabled to play an integral part in safety (DH, 2006b). This was highlighted in the 'Francis Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry'. This inquiry was the result of high mortality rates at one NHS hospital in Stafford between 2005 and 2009. The report found that the "*appalling suffering of many patients*" was primarily caused by a serious failure of a provider Mid Staffordshire NHS Foundation Trust board to listen sufficiently to its patients and staff or ensure the correction of deficiencies brought to the trust's attention (Francis, 2013). The Chair of the Inquiry, Robert Francis QC, made 290 recommendations for improvements which

aimed to improve organisational culture through greater openness, transparency and candour.

To illustrate how patients were not listened to, the case of John Moore-Robinson was cited in the report. He was a young man who went to A&E at Stafford Hospital following a mountain bike accident. He was examined by a junior doctor but despite protests from himself and his friends he was discharged with analgesia. When he left the hospital he was in a wheelchair because he could not walk and was being sick. John collapsed at home in the early hours of the next morning and died of a seizure brought on by massive blood loss. Later found to have been suffering from a ruptured spleen, the signs and symptoms were evident the day before and it is possible that he could have been saved if he had had a proper diagnosis and appropriate treatment (Francis, 2013).

This example was not isolated and the report described many other examples of patients not being listened to and highlighted a wide range of failings across the trust, including a board focused on finance at the expense of quality of patient care, understaffing and a culture of poor practice and neglect that staff felt powerless to change (Thorlby et al., 2014). After the initial 2010 public inquiry and report of the Mid Staffordshire NHS Foundation Trust, the Health and Social Care Act (2012) was passed; this emphasised the importance of putting the patient first by providing details of how to increase the patient voice. Regarding patients there was to be *“no decision about me without me”* (DH, 2012).

The year following the Francis Report there were a number of reviews and reports including Berwick's review into patient safety, 'A promise to learn – a commitment to act' (National Advisory Group on the Safety of Patients in England, 2013), and 'Patients First and Foremost' (DH, 2013a). The latter report summarised initiatives which were directly or indirectly in response to a report related to the Francis report and illustrate the complexity of the problem. It highlighted five new initiatives or concurrent reviews of patient safety (National Advisory Group on the Safety of Patients in England 2013), quality and safety in 14 hospital trusts with persistently high mortality rates (Keogh, 2013), the employment of healthcare assistants

(Cavendish, 2013), the handling of complaints (Clwyd and Hart, 2013) and the development of hospital ratings and the burden of NHS bureaucracy (Thorlby et al., 2014).

Perhaps the Berwick Report highlights the importance of the patient's voice most effectively. It recommended that "*patients and their carers should be present, powerful and involved at all levels of healthcare organisations from wards to the boards of Trusts*" (National Advisory Group on the Safety of Patients in England, 2013). The report acknowledged that "*involvement means having the patient's voice heard at every level of the service, even when that voice is a whisper*". The Berwick Report, similarly to the Francis Report, also identified the importance of the patient's voice at the frontline and at the interface between patient and clinician, for example, when John Moore-Robinson and his relatives tried unsuccessfully to 'speak up' to get him further treatment when he first went to A&E (Francis, 2013; National Advisory Group on the Safety of Patients in England, 2013 p.18).

These initiatives, reviews and reports all highlight the complexity of delivering safe care and the importance of patient and public involvement in safety and that the "*patient's voice should be heard at every level of the service*" (National Advisory Group on the Safety of Patients in England, 2013). What is lacking is how patients can effectively be part of the solution, particularly in the arena of being heard and responded to when they speak up about health concerns.

## **2.3 Policies, enquiries and reports on quality and safety of maternity care**

Pregnancy and childbirth have traditionally been seen as a normal physiological process with high expectations of a healthy outcome for the mother and baby. Safe care in maternity services should mean the reliable reduction of risk of harm to both mother and baby during pregnancy, childbirth and the postpartum period (King's Fund, 2008). If women or their babies become unwell the transition from

routine to emergency care can occur rapidly and unexpectedly (King's Fund, 2008).

Measurements of safety in maternity care have been collected by a number of different organisations over the years with the Confidential Enquiry into Maternal Deaths (CEMACH) being cited as of the world's longest-running clinical audit, (Yentis, 2011). Its aim was to monitor and reduce maternal deaths and improve the safety of childbirth and it has been held in the UK every three years since 1952 to assess the main causes of maternal deaths and, through identification of avoidable causes, to reduce maternal morbidity and mortality by recommending improvements in clinical and service provision (Weindling, 2003). Over the years it has transitioned and changed names, as can be seen in the examples below which include:

- MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries) collaborations commissioned by the Healthcare Quality Improvement Partnership (HQIP). Since 2012 MBRRACE-UK has published an annual report and now each contains the Confidential Enquiry into Maternal Morbidity (CEMM);
- The Confidential Enquiry into Maternal and Child Health (CEMACH), which following a review in 2008 led in 2009 to CEMACH's becoming an independent charity; the Centre for Maternal and Child Enquiries (CMACE), with the programme commissioned mainly by the National Patient Safety Agency (NPSA) (Yentis, 2011);
- The NHS Litigation Authority (NLA); the Clinical Negligence Scheme for Trusts (CNST);

In 2016 The Safer Maternity Care action plan was announced to improve safety of maternity care in the NHS (DH, 2016). The action plan includes resources for maternity training to learn from mistakes and share openly and transparently across the UK and a safety innovation fund to help create new ideas for improving maternity care. Of note is that there is no specific plan for improving women's participation in their own safety.

Quality and safety of care in maternity care have also been recognised by the National Service Framework for Children, Young People and Maternity Services and by organisations including the National Institute for Health and Care Excellence (NICE), the National Patient Safety Agency (NPSA), the King's Fund Review of Safety and the Healthcare Commission's (HCC) review of maternity services in England, 'Towards Better Births' (Healthcare Commission, 2008). 'Maternity Matters' recognised the need to improve safety and emphasised the importance of maternity services providing high-quality, safe and accessible services that are both women-focused and family-centred (DH, 2007). This was superseded by the National Maternity Review, 'Better Births: Improving outcomes of maternity services in England', which not only recognised quality care but also highlighted the importance of the individual woman. *"Every woman, every pregnancy, every baby and every family is different. Therefore, quality services (by which we mean safe, clinically effective and providing a good experience) must be personalised"* (NHS England, 2016).

Data collected from 2003 to 2006 by the NPSA recognised that many of the incidents reported in general healthcare were a result of failures to recognise complications and subsequent delays in treatment (NPSA, 2007b). These findings are similar to the conclusions of the MBRRACE-UK and CMACE enquiries. These enquiries were preceded by CMACE enquiries, which analysed maternal deaths in the UK and Ireland and produced a report every three years with the aim of making maternity care safer. Although the names of the reports have changed over time, similar patterns in organisational failures can be seen.

In the report covering the years 1997 to 1999 the CEMACH assessors found that 60 percent of maternal deaths were associated with some form of substandard care (Lewis G et al., 2001). An example of this was the failure to appreciate the severity of illness and consequent suboptimal treatment and failure of junior staff to diagnose or refer a case to a more senior colleague.

The following report cited that 67 percent of direct maternal deaths were judged to be at least partly due to substandard care, with similar reasons (Lewis et al., 2004)

and in the report covering 2003 to 2005 the report identified that 64 percent of direct deaths were associated with substandard care. The last-mentioned report identified poor or non-existent team working and, again, failure to share relevant information (CEMACH, 2007). None of these reports considered the role of women and their families speaking up about a health deterioration, but did identify failure of healthcare workers to recognise a deterioration in health and poor escalation communication within teams. These factors were seen to affect the 'timeliness' of the response of healthcare workers. Timeliness can be defined as where waits and harmful delays are reduced for both patients and those who give care (Berwick, 2002). The reports did not identify what factors would affect the timeliness of healthcare workers' responses if women did speak up with a deterioration in health, but it is possible that similar factors such as failure to share relevant information could also be important.

The 2007 CEMACH report listed 10 recommendations which were designed to be audited. One of these was to use early warning systems, modified early obstetric warning system (MEOWS), to assist in the detection of deteriorating health (CEMACH, 2007). However, at the time there was no evidence of the benefit or value to this in maternity care (Bick et al., 2014). An ethnographic study found wide variation of results of the implementation of a MEOWS in maternity care settings (Mackintosh et al., 2014). This research also highlighted that the MEOWS chart itself should only be part of the intervention to detect patient deterioration and should be used as an 'alert' for the need for further patient assessment, alongside other tools such as patient involvement (Bick et al., 2014; Mackintosh et al., 2013; Smith et al., 2013).

A consistent finding of the annual and triennial reports, relevant to this PhD research, was that that socially disadvantaged and excluded women were at higher risk of death during or after pregnancy than other women (Knight et al. 2014; CMACE, 2011). The perinatal mortality report also identified this and showed that women from non-white ethnic groups and women in the most deprived quintile had stillbirth and neonatal death rates twice those of white women and those resident in



least deprived areas (CMACE, 2011). This report identified that complex social factors associated with an increased risk of maternal death include contact with child protection services or social services, substance misuse, domestic abuse, being single, being unemployed, having a partner who is unemployed or employment unclassifiable, being a recent migrant to the UK and speaking no English. Women of Black African and Black Caribbean origins had a higher risk of maternal mortality than women from other ethnic backgrounds (CEMACH, 2009). These findings recommended the development of NICE guidelines for care for women with complex social factors (NICE, 2010b). In these guidelines the importance of women-centred care is again reiterated, with the recommendation that women are offered the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals (NICE, 2010b). Interestingly, the eighth CMACE report showed a reduction in the inequalities gap and an overall fall in maternal deaths in the UK but a rise in the number of women dying from an infection (CMACE, 2011).

In addition, since this research was completed further MBRRACE reports have been published; they show that quality of care affected the mortality rate of 225 babies who died after 37 weeks' gestation in 2015 (MBRRACE-UK, 2017). The enquiry found that there were problems with adequate staffing and resources to provide safe care, and that during antenatal care there were missed opportunities to identify babies who may have need for further monitoring (MBRRACE-UK, 2017). Also since this research was completed, and significant to this study, the MBRRACE report that surveyed maternal deaths in the UK between 2012 and 2014 identified that there have been improvements to mortality rates of women with hypertensive disorders of pregnancy (Knight et al., 2016). The implications of these latest MBRRACE findings will be discussed in Chapter 8.

These reports are important for this PhD study for many reasons. Pre-eclampsia can affect all women, but women of Black Caribbean and Black African origins are at higher risk of developing pre-eclampsia (NICE, 2016) and are shown to have poorer outcomes in many of the reports highlighted above. As the reports

highlighted the impact of social deprivation and poorer outcomes, for this study it was important to recruit a range of women and family members from different ethnicities and social backgrounds to give a greater understanding of help-seeking with pre-eclampsia in order to explore if women from a range of social backgrounds and ethnicities did have different experiences. Informed decision-making was highlighted in the NICE guidelines for care for women with complex social factors (NICE, 2010b); in the UK it is not known if women are informed about pre-eclampsia and if they are able to help seek with this information. To understand more about the factors that may impact on help-seeking for pre-eclampsia, a systematic review and narrative synthesis of qualitative literature of help-seeking with signs and symptoms of pre-eclampsia will be described in Chapter 4.

In addition to the organisational factors highlighted above affecting timeliness of care, there is growing evidence that women and their families do not always feel listened to or receive an appropriate response from healthcare professionals (Redshaw et al., 2014; Care Quality Commission (CQC), 2013; Rance et al., 2013). A CQC survey showed that out of a random sample of over 23, 000 women who gave birth in February 2013, 19 percent felt their concerns during birth and labour were not taken seriously (CQC, 2013). A 2014 Stillbirth and Neonatal Death charity (Sands) report cited that of the women whose babies died before labour, only 57 percent felt listened to, or that their concerns had been taken seriously. Of the women whose babies died during labour, a quarter felt that staff communicated poorly, almost half did not feel listened to, and around 10 percent reported rarely or never having trust or confidence in the staff caring for them during labour and birth (Redshaw et al., 2014). The most common finding for women and partners whose baby died before labour was that 72 percent recognised that something was wrong with changes in their babies' normal pattern of movement (Redshaw et al. 2014). When asked about raising their concerns to healthcare professionals, a third of women reported contacting a clinician straightaway and 46 percent within 24 hours, yet only 57 percent felt listened to at this time and 39 percent were confident of decisions made (Redshaw et al., 2014). This is important, as a

significant reduction in sudden alteration in or absence of fetal movements may be a warning sign of impending fetal death. The Royal College of Obstetricians and Gynaecologists (RCOG) recommends that “*women should be aware of fetal movements up to the onset of labour and should report any cessation or decrease in movements to their maternity unit*” (RCOG, 2011 p.3).

It is possible that changes in fetal movements is one of the signs women could look out for due to the high incidence of small-for-gestational age (SGA) babies whose mothers have pre-eclampsia. Although it did not link SGA to pre-eclampsia, a large Norwegian study explored maternal characteristics and pregnancy outcomes in women presenting with decreased fetal movements in late pregnancy and found decreased fetal movements were associated with adverse pregnancy outcome in 26 percent, including preterm birth and fetal growth restriction (Tveit et al., 2009). In a UK perinatal mortality report, cited in NICE guidelines, SGA babies were common in 20 to 25 percent of preterm births and 14 to 19 percent of term births in women with pre-eclampsia being less than the tenth centile of birth weight for gestation (NICE, 2011). Currently women are not routinely advised that reduced fetal movements could be an early warning sign of pre-eclampsia either in the RCOG guidelines or the NHS Choices guidelines (NICE, 2016; NHS, 2015; RCOG, 2014). Although the reasons for high stillbirth rates are complex and need further exploration there is evidence in the UK that families’ voices are not heard when speaking up about a change in the normal pattern of fetal movements and this could affect timeliness of care (Redshaw et al., 2014).

Despite national guidelines much of the advice available for women regarding signs and symptoms of potentially adverse health outcomes in pregnancy and postpartum have been developed by charitable organisations such as Action on Pre-eclampsia (APEC), Tommy’s, Sands and MAMA (Mums and Midwives Awareness) Academy. Many of these charitable campaigns can be accessed online. Specific examples include: APEC regarding a checklist of the signs and symptoms of pre-eclampsia (Action on Pre-eclampsia, 2014); and the MAMA Academy which has a website where the public are able to download their own

'daily movements checker' specifically to alert women about the risks of reduced fetal movements and to give them the confidence to ask for help (MAMA Academy, 2014). There is a growing recognition that the internet is now where many women seek information (Sayakhot and Carolan-Olah, 2016; Lynch and Nikolova, 2015; Lowe et al., 2009; Romano, 2007). What is not known is how this information is used for help-seeking, including for those women who are at risk of or have pre-eclampsia. In addition, Sands is co-funding a large ongoing study, Awareness of Fetal movements and Focusing Interventions Reduce Fetal Mortality (AFFIRM), which is looking at the way maternity units respond to women with reduced fetal movements in 36 units in Britain (Norman, 2013).

NICE guidelines for routine postnatal care of women and their babies published in 2006 contain information to support women and families identify and know how or when to seek help about concerns about a sudden deterioration in maternal and infant health. The guidelines recommended that all women and their families were made aware within 24 hours of giving birth of potentially life-threatening conditions both to themselves and their babies in the postnatal period, including signs and symptoms of health deterioration which should 'trigger' their self-referral to appropriate health services, including when the emergency services should be called (NICE, 2006). A Royal College of Midwives report (RCM) report, Postnatal Care, looked at implementation of NICE quality standards on postnatal care and found that 47 percent of mothers surveyed on the website Mumsnet were not aware of signs of health deterioration in the postnatal period, despite NICE recommendations (RCM, 2014); without knowing what signs and symptoms to look out for, it is possible that this would affect help-seeking in the postnatal period.

## **2.4 Summary**

This background chapter has highlighted the growing recognition of the importance of patients being involved in their own safety in policies, enquiries, guidelines and reports. As in the help-seeking literature, many sociological, psychological and organisational factors have been identified that may affect specific safety strategies

involving the patients and public. However, there is a paucity of research into what factors may affect this occurring in maternity care. There is even less research available into the difficulties women and their families may have raising health concerns and having these responded to.

Help-seeking theories can be used to further understand the factors that may affect women and their families escalating their concerns over a deterioration in health, and healthcare workers' ability to respond. Chapter 3 will examine different approaches to help-seeking, including the rationale for selecting theoretical frameworks, including Candidacy Theory (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005), Lipsky's concept of Street Level Bureaucracy (Lipsky 2010), and the Symptom Perception Theory (Moller-Leimkuhler, 2002; Gijsbers Van Wijk and Kolk, 1997).

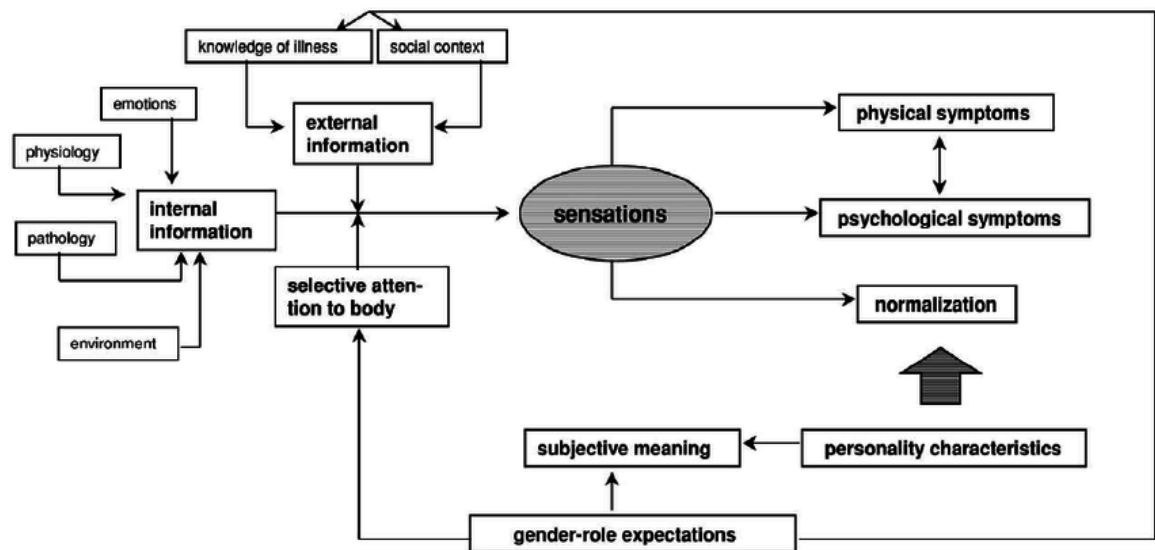
## **Chapter 3: Approaches to understanding help-seeking and provider responses**

This chapter will explore different approaches to help-seeking to understand what factors may affect women and their families help-seeking with pre-eclampsia, and the provider response. Help-seeking theories include “Symptom Perception Theory” (Moller-Leimkuhler, 2002; Gijssbers Van Wijk and Kolk, 1997) and Candidacy Theory (Dixon-Woods et al., 2006; Dixon Woods et al., 2005). To understand factors affecting healthcare workers’ responses, Lipskys’ social theory of Street-level Bureaucracy (SLB) (Lipsky, 2010) will be discussed with relevance to how healthcare workers’ responses to help-seeking may be affected at the front-line of a busy organisational system such as the NHS. This chapter will inform the subsequent systematic review in Chapter 4 and the research aims and objectives, design and methods in Chapter 5.

### **3.1 Symptom Perception Theory**

Many factors have been identified that affect an individual’s help-seeking behaviour. These include influences such as: knowledge of the disorder; identification of the symptoms; psychological factors such as anxiety; and attitudes and social factors including competing priorities, lack of support from family and friends, and situational factors (Scott and Walter, 2010; Mahony and Hegarty, 2009; Shaw et al., 2008; Smith et al., 2005; Bish et al., 2005; Rickwood et al., 2005; Greenlund et al., 2004;). Many believe that the first step to seeking help is the identification of the symptoms of the disorder or illness (Hay, 2008; Gijssbers Van Wijk and Kolk, 1997; Kolk et al., 2003); authors have identified that help-seeking can occur when there is a change in health or symptoms perception (Scott and Walter, 2010; Mahony and Hegarty, 2009). The importance of signs and symptoms of pre-eclampsia to aid help-seeking was identified in Chapter 1 (NICE, 2016; RCOG, 2012).

An early theory which explored symptom perception is the Symptom Perception Theory. In this theory six chronological steps were identified that allow help-seeking to occur. These include input of somatic sensation, selection of information through attentional processes, detection of somatic sensations, attribution of sensations to somatic or psychological causes, the role of personality characteristics such as somatisations and negative affectivity, and the output of the model in terms of somatic or psychological distress and illness behaviour (Moller-Leimkuhler, 2002; Gijsbers Van Wijk and Kolk, 1997). Moller-Leimkuler et al. later adapted the model in 2002 (see Figure 1 below), adding important dimensions, for example, how external information such as knowledge of illness and social context, and the impact of individual personality characteristics can affect help-seeking (Moller-Leimkuhler, 2002).



**Figure 1 Moller-Leimkuhler, 2002 Model of symptom perception (adapted and modified from Gijsbers van Wijk and Kolk, 1997)**

It can be seen from Figure 1 that the researchers believed that information was a key component of symptom perception. Knowledge of a specific disorders' signs and symptoms affecting help-seeking has also been alluded to by many other authors, but mainly in relation to the identification of chronic conditions such as

cancer, mental health disorders and urinary incontinence (Scott and Walter, 2010; Shaw et al., 2008; Mahony and Hegarty, 2009; Bish et al., 2005; Smith et al., 2005; Rickwood et al., 2005; Greenlund et al., 2004; Rickwood and Braithwaite, 1994). This is similar to individuals becoming the 'expert patient' (DH, 2001a). Here the belief is that by developing education programmes and creating expert patients, individuals are better able to take responsibility for self-management of their own long-term healthcare needs. More recently, 'self-management' was recognised in a government statutory guidance document highlighting the importance of involving patients in their care (NHS England, 2017). By recognising patients as experts in their own health and by providing support to develop understanding and confidence, self-management leads to improved health outcomes, improved patient experience, reductions in unplanned hospital admissions, and improved adherence to treatment and medication (NHS England, 2017 p.10). However, self-management or expert patient research to date has been confined to individuals with chronic diseases such as diabetes (Snow et al., 2013), whereas pre-eclampsia is a specific disorder of pregnancy that can occur without warning (NICE, 2016).

Pregnancy and childbirth differ from chronic illness in many ways. Traditionally there are those who see it as a natural process rather than an illness or disorder (Kukla and Wayne, 2016) and typically it is associated with positive emotions and with motherhood (Geller, 2004). The counterview to this is those who conceptualize pregnancy as a dangerous time wherein a woman and her fetus are at risk and in need of constant medical monitoring and intervention (Parry, 2008). Another difference from chronic illness is the disorder itself. Although some women are more at risk of developing pre-eclampsia it can occur in any woman and her health can deteriorate very quickly with very little warning (NICE, 2016). Some women with high-risk pregnancies will have straightforward pregnancies and some with low-risk pregnancies may develop complications or have unexpected adverse outcomes involving maternal and/or neonatal morbidity and mortality (Lee et al., 2012 ; MacKenzie Bryers and Van Teijlingen, 2010). Another difference from chronic illness is the addition of the fetus, where maternal and fetal health can



sometimes be separate entities. This may impact on symptom perception and help-seeking.

Normalisation was an important dimension identified in Figure 1. Normalisation is often discussed in terms of chronic illness. It is defined by Bury (2001) as having two kinds of processes: the first is where patients may try to 'normalise' their illness and try to keep their pre-illness lifestyle and identity intact; and the second is the incorporation of illness into the patient's changed lifestyle where patients will try to keep their pre-illness lifestyle and identity intact, and this may involve the maintenance of as many activities as possible and the disguising or minimisation of symptoms in behaviour and in accounting processes (Bury, 2001). Hay (2008) also found that interpretation of symptoms is tentative and conditional on other cultural information.

In pregnancy this could be seen as women trying to protect their existing normal pregnancy, projected birth plans and their future plans of a normal lifestyle with their new baby or babies. The concept of normalisation could be seen to be similar to Parry's belief that some women are resistant to the medicalisation of their pregnancy and childbirth experiences, and actively assert their agency over medicalisation, thus shaping their own pregnancy and birth experiences (Parry, 2008). Again, little is known about normalisation in pregnancy so this is important as it may impact on women seeking help with signs and symptoms of pre-eclampsia.

For pre-eclampsia it may not be normalisation that impacts on help-seeking but rather women and their families' understanding of how serious the signs and symptoms of the condition could be. This is similar to studies of patients' experiences of help-seeking for acute illnesses such as signs of a stroke and heart attack and more relevant for women with pre-eclampsia which often has a sudden onset. A study on help-seeking with cardiac signs and symptoms found that patients delayed seeking help for stroke and heart attack symptoms as they perceived that their symptoms did not match those traditionally advertised in public health campaigns (Henriksson et al., 2012; Greenlund et al., 2004). Likewise, a

stroke study found that as some patients perceived their symptoms to be mild and not readily recognisable as stroke they did not consider calling the emergency services (Mackintosh et al., 2012). Leventhal et al. (2004) found that symptoms of deteriorating health may be misleading in terms of their diagnostic value as severe symptoms may be associated with a mild illness and yet a more serious illness may manifest itself without obvious signs and lead to unnecessary delays in seeking help (Leventhal et al, 2004). It is possible that women help-seeking with signs and symptoms of pre-eclampsia may be affected by the confusion of whether their signs and symptoms are significant enough to escalate to a healthcare worker.

Leventhal et al.'s Common Sense Model (CSM) of illness representations, another help-seeking model, also identified that the use of information and social and psychological factors influenced help-seeking (Leventhal et al., 2016; Meyer et al., 1985; Leventhal et al., 1980). The CSM evolved from a study conducted in the 1960s examining how a community responded to the 1957 flu pandemic; data showed that participants who experienced symptoms or saw a family member or a close friend fall ill were more likely to believe they were at risk and take action (Leventhal et al., 2016). The CSM highlighted how patients use three basic sources of information for help-seeking: first is the general pool of 'lay' information already assimilated by the individual from previous social communication and cultural knowledge of the illness; second is the information from the external social environment from perceived significant others or authoritative sources such as a doctor or parent; and third is that the individual's current experience with the illness which he or she takes into account when completing his/her illness representation (Hagger and Orbell 2003). This could be significant for women help-seeking with pre-eclampsia, not only for women who have had pre-eclampsia once and are at greater risk of having it again in a future pregnancy, but also for women who may have seen friends or family members experience pre-eclampsia. Currently there is little research available in this area.

## 3.2 Candidacy Theory

Many authors have identified that even with information, detection and experience of symptoms may not automatically lead to the patient seeking help, with many complex, psychological and social reasons for this (Leventhal et al., 2016; Scott and Walter, 2010; Martin and Leventhal, 2004; Kolk et al., 2003; Kolk et al., 2002; Moller-Leimkuhler, 2002; Gijsbers Van Wijk & Kolk, 1997; Leventhal et al., 1980). One theoretical framework that includes many of the aspects above and could be used in conjunction with the help-seeking theories is Candidacy Theory. This was developed by Dixon-Woods et al. (2005) following a critical interpretive synthesis of literature on access to healthcare by vulnerable groups (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005). This theory states that how people recognise their symptoms as needing medical attention or intervention is key to understanding how they assert a claim to candidacy (Dixon-Woods et al., 2006).

Candidacy is a dynamic concept; it describes how people's eligibility for healthcare is determined between themselves and the health services and is defined as the ways in which peoples' eligibility for medical attention and intervention is jointly negotiated between individuals and the healthcare service (Dixon-Woods et al., 2006). The ease with which people can gain access to healthcare services is described as "permeability" by Dixon-Woods et al. (2005).

Previously other researchers used it to analyse help-seeking trajectories mainly for vulnerable groups accessing services, including: asylum-seekers; the elderly; patients accessing emergency care with long-term conditions; those with multiple sclerosis, mental health problems and intellectual disability; sex workers needing primary care; and children (Chase et al., 2017; Abbott et al., 2017; Chinn and Abraham, 2016; Methley et al., 2016; Mackenzie et al., 2013; Hunter et al., 2013; Bristow et al., 2011; Gideon, 2011; Kovandzic et al., 2011; Coupland and Maher, 2010; Koehn 2009; Dixon-Woods et al., 2006), but no one has used it to explore help-seeking and pre-eclampsia.

There are seven overlapping stages in the process of negotiating candidacy: identification, navigation, permeability of services, appearing at services and asserting candidacy, adjudications by professionals, offers of resistance, and operating conditions (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005). Mackenzie et al. (2013) performed a critical interpretative literature analysis to see if 'candidacy' was a useful concept to understand how vulnerable groups accessed and utilised health services. Mackenzie et al. (2013) describe each stage, but importantly emphasise the cyclical nature of individual trajectories through these stages (Table 1).

**Table 1 Negotiating the candidacy journey for health services - an exploration from Dixon-Woods et al. 2006**

<b>Stages of candidacy</b>	<b>Description of stages</b>
Identification of candidacy	Process by which individuals come to view themselves as legitimate candidates for particular services
Navigation of services	Knowing how to make contact with appropriate services in relation to identified candidacy
Permeability of services	Includes the level of explicit and implicit gate-keeping within a service and the complexity of its referral systems; in addition it refers to the 'cultural alignment' between users and services
Appearing at services and asserting candidacy	The work that individuals must do to assert their candidacy in an interaction with a healthcare professional
Adjudication by professionals	Candidacy as expressed by service-users is validated or otherwise by healthcare professionals and this influences subsequent offers of services
Offers of, resistance to, services	Emphasises that follow-up services may be appropriately or inappropriately offered and that these may or may not be acted upon by service-users
Operating conditions and local production of candidacy	This incorporates factors that influence decisions about subsequent service provision (e.g. the resources available for addressing candidacy) and the kinds of contingent relationships that develop between professionals and service-users over a number of encounters

They concluded that 'candidacy' as a theory was a useful framework, but felt that a greater understanding of how multiple factors influenced candidacy would be beneficial. They also felt an understanding of the impact of the financial restraints

that organisations are facing needs further investigation. The individual factors influencing help-seeking and pre-eclampsia are not known, highlighting that this research could add to the understanding of candidacy in general but also understanding of specific individual help seeking factors for pre-eclampsia.

Later research used candidacy as a framework for understanding access to care for asthma in British South Asian children (Hudson et al., 2016). The study used a qualitative approach and used semi-structured interviews of 49 parents of children with asthma to understand the barriers to effective and accessible asthma care. Using interpretive thematic analysis the researchers found candidacy was a useful framework and was similar to Symptom Perception Theory as they identified parents' ability to claim candidacy at health services was affected by a low level of awareness of asthma prior to diagnosis and uncertainty about symptoms (Hudson et al., 2016). The importance of knowledge and confidential, easily accessible services was similarly highlighted by Normansell et al. (2015) in a qualitative study from 2013. Qualitative semi-structured interviews were conducted at an inner London further education college with 17 women aged 16 to 25 using the candidacy framework to explore access and attitude to regular sexual-health screening on intercity multi-ethnic students (Normansell et al., 2016).

Other factors were seen to affect help-seeking, for example, long waiting times and services perceived to be hostile or insensitive impacted on candidacy for these young women (Normansell et al., 2016). Similar findings of unfavourable 'adjudications' by gatekeepers were found by Chase et al. (2017) in their qualitative research which explored candidacy in the help-seeking trajectories of 25 asylum-seekers in Montreal, Canada. For example, asylum-seekers found administrative procedures specific to asylum-seekers cumbersome, and they were affected by long waiting times and felt discriminated against by hostile attitudes towards asylum-seekers (Chase et al., 2017). Sometimes asylum-seekers trying to access healthcare services were either refused care or offered it with a fee (Chase et al., 2017). Both asylum-seekers requiring healthcare and healthcare workers were

confused about what information was correct. Similar to the study by Normansell (2016), permeability of the services also affected access.

When looking at permeability of services for parents of children with asthma, it was seen to be facilitated for families who had access to a specialist practice nurse, but not all families had this (Hudson et al., 2016). This could be similar to women with pre-eclampsia who have continuity of care and a named midwife. Midwife-led continuity of care has been defined as care where *“the midwife is the lead professional in the planning, organisation and delivery of care given to a woman from initial booking to the postnatal period”* (RCOG, 2001). A recent Cochrane Review comparing different maternity care models suggested that women who received midwife-led continuity models of care were less likely to experience intervention and more likely to be satisfied with their care with at least comparable adverse outcomes for women or their infants than women who received other models of care (Sandall et al., 2016). The review did not explore help-seeking and pre-eclampsia, but did show that these women had improved experiences.

Theories of help-seeking, including Symptom Perception Theory and Candidacy Theory, have identified many individual factors that can contribute to help-seeking: knowledge, symptom perception, normalisation, permeability of services, and adjudications by healthcare workers. Many of these could also be factors which facilitate or hinder women’s help-seeking in pre-eclampsia and need exploration. To understand what may affect negotiating in the healthcare service from the healthcare worker perspective, the role of healthcare workers needs further analysis. To illuminate factors affecting healthcare workers’ responses Lipsky’s social theory of Street-level Bureaucracy (SLB) (Lipsky, 2010) may be useful and is discussed below. This theory was selected to contribute to understanding how healthcare workers’ responses may be affected by micro, meso and macro factors of the organisation.

### 3.3 Street-level Bureaucracy Theory

Although one definition of help-seeking defines it as a “*a three-way interactive process that involves the recipient, the helper and the task or problem*” (Nadler 1987), very few theories explore help-seeking from the helpers’ perspective. This definition was derived from research in Tel Aviv which explored how the characteristics of the helper, the task and the recipient affect the willingness to seek help (Nadler, 1987). Participants were observed working on a difficult anagram task, 96 males and 32 females (16 to 17-year-olds), some identified with high self-esteem and others with low self-esteem. Their actual help-seeking behaviour served as a dependent measure (Nadler, 1987). His findings indicated that help-seeking is a complex behavioural phenomenon which is determined by the characteristics of the task, the helper and the person needing help. He found that willingness to seek help was determined by the self-esteem of the person needing it; those with lower self-esteem sought help the least. He felt his findings highlighted the necessity to consider the needy population, the available helpers and the nature of the problems (Nadler, 1987). Although this definition was from an experiment with teenagers and not health-related, it is one of the few definitions of help-seeking that includes three components i.e. the recipient, the helper and the task, and therefore it is appropriate for this research, which explored women’s, their families’ and healthcare workers’ perspectives on help-seeking with pre-eclampsia in an NHS organisation. The research also highlighted the importance of individual characteristics for example, how self-esteem affected help-seeking. This may be relevant to this PhD research where it is not known at the time of publication if personality traits such as self-esteem affect help-seeking for women with signs and symptoms of pre-eclampsia and if this affects how healthcare workers respond to the women.

However, it is acknowledged that this definition is simplistic and does not fully explore the complex social, psychological and organisational structural aspects that can hinder or facilitate help-seeking. As mentioned above, Candidacy Theory could be useful to understand negotiating and help-seeking from women’s and

families' perspectives, but another theoretical framework may be needed to explore what affects healthcare workers' ability to respond or how they impact on help-seeking; as mentioned above, the helper is viewed as integral in Nadler's definition of help-seeking (Nadler, 1987). Factors affecting the helper could be further understood by using Lipsky's social theory of Street level Bureaucracy (Lipsky, 2010) to elucidate responses of healthcare workers to women and their families with pre-eclampsia. He sought to explain the working practices and beliefs of front-line workers faced with systematic and practical dilemmas that must be overcome (Cooper et al., 2015).

He used the term 'street-level bureaucrats' to describe teachers, judges, police officers, health workers, social workers, police defenders and more. He believed that help-seeking is dehumanising as the healthcare workers or street-level bureaucrats are unable to provide responsive and appropriate services due to the environment and conditions they work in. He believed they possess common traits such as discretionary decision-making and have relative autonomy from management. For Lipsky, *"discretion occurs in a context of conflict between front-line workers and managers: between a desire for top-down control and local opposition to it. But it also occurs in a context in which any policy has to be applied and understood alongside other policies and has to be tailored to available resources and circumstances, namely 'complex tasks for which elaboration of rules, guidelines, or instructions cannot circumscribe the alternative'"* (Evans, 2011; Lipsky, 1980). This could be applicable to healthcare workers delivering maternity care on the frontline who may have the discretion to decide how to deliver quality, safe care to women and their families help-seeking, whether this is following institutional guidelines or not. Currently there is no research available that has utilised SLB as a framework specifically in the field of help-seeking or pre-eclampsia, so other more general research in maternity will be needed to explore if SLB is a suitable framework for this research.

Lipsky believed that in order to process large numbers of clients, street-level bureaucrats develop routines and simplifications to ration services and control



clients (Adami, 2010) and in so doing the ability to provide individual attentive service is compromised (Finlay and Sandall, 2009). Lipsky believed that demand from clients will always outstrip supply of finite resources (cost, time or service access) and as a result employees must resort to 'mass processing' of excessive client caseloads (Cooper et al., 2015; Lipsky, 2010). Maternity services in the UK, similar to other organisations Lipsky studied, are known to have large numbers of clients and can be very busy; press releases have highlighted this. For example, in a *Guardian* article, research by the Labour Party found that 42 hospital trusts had been forced to close maternity wards 382 times in 2016, with many blaming staff shortages, high activity and bed and cot capacity (Asthana, 2017). The figure of 382 was higher than that of 375 the previous year, and an almost 70% increase on 225 in 2014 (Asthana, 2017). It is possible that when organisations are so busy they have to temporarily close wards that this may directly impact on factors affecting help-seeking both for women and families, but also for the healthcare workers responding. Although there was a paucity of research in maternity that has used SLB to illuminate and further understand healthcare workers responding to help-seeking, a few papers highlight how it has been used in other aspects of maternity.

One worldwide meta-synthesis of 14 midwives' experience of hospital practice in publicly funded settings explored discourses around midwifery work in the modern, risk-averse and consumerist childbirth context (O'Connell and Downe, 2009), and alluded that SLB Theory could highlight the quality of care delivered. They found on some hospital labour wards, midwives were often required to care for a number of women at a time and the heavy workload led them to provide a task-based approach to care, compromising individualised care (O'Connell and Downe, 2009). This possibly demonstrates how SLB Theory affects care i.e. employees must resort to 'mass processing' of excessive client caseloads (Lipsky, 2010). However, their findings also highlighted that despite heavy workloads midwives tried to provide an equitable service for all women (O'Connell and Downe, 2009). In summary, their findings suggested that although midwives wanted to provide

women-centred care while supporting normal birth, in practice there was an acceptance that hospital-based maternity care is inevitably based on medical protocols and emerging technology and as a consequence midwives accept intervention as a 'normal' part of birth (O'Connell and Downe, 2009). This study could be relevant to this PhD study as women with pre-eclampsia often follow a care pathway guided by medical guidelines and protocols such as NICE pre-eclampsia guidelines (NICE, 2016), and this could impact on how healthcare workers respond to women and their families help-seeking with pre-eclampsia.

Finlay and Sandall (2009) also drew on Lipsky's SLB Theory to understand how midwives working in one UK inner-city NHS maternity service provider managed competing demands of delivering a personalised service within a bureaucratic NHS system looking at standard care and caseload care models. They also identified the conflict between the needs of the organisation and the needs of the women especially for the standard care model (Finlay and Sandall, 2009) recognising Lipsky's quote "*street level bureaucracy must find a way to resolve the incompatible orientations towards client-centred practice on the one hand and expedient and efficient practice on the other*" in their findings. They felt that staff who did not follow the continuity of care model showed more allegiance to the organisation than to their individual clients (Finlay and Sandall, 2009).

This allegiance to the organisation rather than the individual woman was also an interesting finding from a systematic review and meta-synthesis of literature on women's experiences of disrespectful care during intrapartum care in sub-Saharan Africa. The research found that although not explicitly stated in the papers, social backgrounds, for example, women's race, poverty or status overtly influenced the timeliness and quality of care they received (Bradley et al., 2016). "*Women deemed 'modern' or 'worthy' often received preferential treatment and deliberate decisions were made to actively withhold, neglect or ignore women deemed 'other'*" (Bradley et al., 2016 p.167). The authors of the systematic review felt that midwives used their discretionary powers in this way, acting as street-level bureaucrats (Lipsky, 1980), attempting to marry the care needs of women with the

demands of the institution and their own overwhelming workloads (Bradley et al., 2016). The systematic review used PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines, and searched databases from 1990 to 6 May 2015, and 25 original studies were included for thematic synthesis.

Although the synthesis was not about help-seeking (and the studies were not from the UK), it did explore midwives' behaviour and revealed that maternity care was institution-centred rather than woman-centred. This systematic review and meta-synthesis could be relevant to the study as it indicated that healthcare workers' responses may not only be affected by the institution they work in, but also by the health workers' bias of who should receive preferential treatment. It suggests SLB Theory could be useful to explore healthcare workers' responses to women help-seeking with pre-eclampsia in an NHS institution.

SLB was also seen to affect quality of care delivered by midwives in an ethnographic study in South Africa on two labour wards (one rural and one urban). The study explored factors that shaped everyday practice of midwives working in district hospitals during the implementation of a public sector reform to improve financial management (Penn-Kekana et al., 2004). The researchers found the multiple demands of implementing the plethora of new reforms took up their time and led healthcare workers prioritising and attempting to implement the most recent policy, or whichever policy was to be inspected next; subsequently managers' demands were prioritised over patients' quality of care (Penn-Kekana et al., 2004). When they compared this to SLB Theory as a way of explaining problems with implementation, they found that the midwives had tried to implement the new policies, but in so doing had compromised patient quality of care in the process.

This contrasted with Lipsky's view, where frontline providers fail to implement reforms that do not conform to their sense of what is right and possible (Lipsky, 1980). Interestingly, these findings contrasted with another ethnographic study in the UK, which found that midwives believed they had real autonomy and exercised it every day (Walsh, 2006). This ethnographic study examined birth centre culture,

observing a new birth centre in the Midlands of England which catered for the births of around 300 women a year (Walsh, 2006). They viewed the use of street level bureaucracy as a pragmatic way of improving the service (Walsh, 2006). These positive results may also have been a result of the culture within that particular birth centre e.g. healthcare workers had raised tens of thousands of pounds to redecorate the birth centre and this may have affected how they worked due to pride in what they had created.

It is difficult to draw conclusions from the five studies identified above as they had different aims and objectives, different methodologies and, in addition, the contrasting findings may have been because the data from two of the studies were from Africa (Bradley et al., 2016; Penn-Kekana et al., 2004) where different organisational systems than in the UK may not make the results comparable. However, each study indicated that SLB Theory could be useful to illuminate factors affecting healthcare workers' delivery of quality care in maternity. They also highlighted the influence that midwives may have, following SLB Theory that public service employees 'on the ground' have real power to effect change, either in line with official policy or to subvert it (Lipsky, 2010; Walsh, 2006).

Significantly, none of the studies were looking specifically at help-seeking; however, Drinkwater et al. (2015) used SLB as a framework to understand how healthcare professionals respond to imposed policies, exploring why patients with long-term conditions use unscheduled care (Drinkwater et al., 2013). Although this study was not directly about help-seeking its aim was to understand how healthcare workers responded to patients who sought help with chronic conditions. It was a qualitative interview study in Northwest England, where 29 healthcare workers from a range of professions were interviewed about who provided primary care or unscheduled care services (Drinkwater et al., 2013). Their findings contrasted to findings from Pennkeener et al. (2004) and Bradley et al. (2016), as they found healthcare workers did not see the use of unscheduled care as a problem and there was limited commitment to the policy targets (Drinkwater et al., 2013) i.e. some practitioners acknowledged that patients with multiple problems in

complex healthcare systems could not always avoid unscheduled appointments. They felt this conflicted with Lipsky's view that "*street level bureaucrats and the devices they invent to cope with uncertainty and work pressures effectively become the public policies they carry out*" (Lipsky, 2010), i.e. the GPs in this study interpreted their role as one of supporting patients navigating through a complex system and described illness exacerbations as inevitable (Drinkwater et al., 2013). They concluded that policy should aim for whole-system change rather than reliance on individual healthcare workers to make changes in their practice.

By using the SLB theory as a framework it may be possible to not only highlight what factors affect healthcare workers' ability to respond, but how this affects patients negotiating at the frontline and could be used in conjunction with the help-seeking theories mentioned above including the Candidacy Theory.

### **3.4 Summary**

Help-seeking theories such as Symptom Perception Theory and Candidacy Theory could aid understanding of help-seeking and could be useful as frameworks to challenge and extend existing knowledge with respect to women's help-seeking behaviour when experiencing symptoms and signs of pre-eclampsia. In order to understand what may affect negotiating in the healthcare service from the health worker's perspective, the role of healthcare worker needs further analysis, and to do this Lipsky's social theory of Street-level Bureaucracy (SLB) (Lipsky, 2010) may be useful. They will be used in as a framework in Chapter 4 below, which will present findings from a systematic review and narrative synthesis of the experiences of women and their families who 'spoke up' about potential symptoms and signs of pre-eclampsia, and the organisational response.

## **Chapter 4: Experiences of help-seeking by women with early warning signs of pre-eclampsia and their families, and the organisational response**

This chapter presents findings from a systematic review and narrative synthesis of the experiences of women and their families who had had early warning signs of pre-eclampsia when seeking help, and the organisational response (see Appendix 1 for a published paper in BMC Pregnancy and Childbirth (Carter et al., 2017).

Following presentation of the findings of the systematic review and narrative synthesis, relevant approaches, theories and frameworks of help-seeking are considered and discussed as suitable frameworks to guide the methodology and to inform the research questions of the study presented in this thesis are discussed.

### **4.1 Systematic review and narrative synthesis**

In order to develop a focused question for the narrative synthesis, which included the women's, their families' and clinicians' perspectives, and to facilitate the literature search, the SPICE (Setting, Perspective, Intervention, Comparison, Evaluation) framework was used (Booth, 2006). The SPICE framework is adapted from the PICO (Patient problem, Intervention, Comparison and Outcome) framework and was more appropriate for the primary research question as it enabled inclusion of all the perspectives of interest.

The following research question was developed for the systematic review:

*“What are the factors that affect women and their families speaking up with early warning signs and symptoms of pre-eclampsia, and what are the factors affecting health professionals' response?”*

Table 2 presents the search terms used.

**Table 2 SPICE Framework Search Terms**

<b>SPICE acronym</b>	<b>Keywords</b>	<b>Examples of alternative words</b>
Setting	Healthcare, systems, caring, providing care for women with pre-eclampsia	Hospital, community care, accident and emergency, maternity ward, antenatal clinic, postnatal clinic, labour ward, delivery suite, birth centre, alongside midwifery units, community clinic, GP surgery
Perspective	Pregnant and postpartum women and their families and healthcare staff	Antenatal, postnatal, pregnancy, labour, birth, obstetric, childbirth/ midwives, obstetricians, managers, maternity support workers, partners, healthcare workers, women
Intervention	Speaking up about pre-eclampsia/ patient participation in safety	Patient involvement, patient collaboration, patient partnership, patient-centred care, decision making escalation of care, early warning systems, signs and symptoms, organisation, management, speaking up, seeking help, help-seeking behaviour, rapid response,
Comparison	Healthcare staff response	Communication, team work, listening, nurse patient relations, midwife patient relations
Evaluation	Women/ families/ healthcare staff response	Perceptions, thoughts, attitudes, behaviours

A narrative synthesis approach was selected as it is systematic and transparent, with guidance on enhancing trustworthiness (Taylor et al., 2015; Sadler et al., 2014; Marshall et al., 2012; Popay et al., 2006). The approach aims to produce a

textual, narrative understanding of findings from included studies conducted in different settings and contexts (Fudge et al., 2016). This was suitable for this study as it enabled the consideration of evidence of the views, experiences and perspectives of women, their families and healthcare workers which were more likely to be generated by qualitative studies.

The UK's Economic and Social Research Council (ESRC) methods programme guidance was used to reduce risk of bias (Popay et al., 2006). This includes a general framework or toolbox of four components: developing a theory, delivering a primary synthesis of findings of included studies, exploring relationships in the data, and assessing the robustness of the synthesis. For the purposes of this review tabulation and thematic analysis were used to analyse the data. Thematic analysis incorporates aspects of the grounded theory approach, which is the process of coding, sorting and organising data, but it does not include theoretical sampling (Dixon-Woods et al., 2006).

## **4.2 Search and selection strategy**

Initially a systematic search of relevant literature was completed. Search strategies were constructed using key headings in SPICE to guide the review. Words from the research question were adapted depending on the database. For example, a combination of free text and the database's own subject headings were used. The following electronic data bases were searched: Medline, CINAHL, HMIC, PsycINFO, Embase, BNI, ASSIA, Scopus, Maternity and Infant Care, Web of Science, Google Scholar, Cochrane, Joanna Briggs Institute and International Biography of Social Sciences with the support of an Information Service Consultant from January 1980 to April 2016. For further details of the search strategy, please see Appendix 2.

### **Inclusion criteria**

English language studies were selected that used a range of qualitative approaches to capture evidence of the experiences of women and individuals in



their immediate social network, such as their partner or other close family member, of pre-eclampsia and eclampsia.

### **Exclusion criteria**

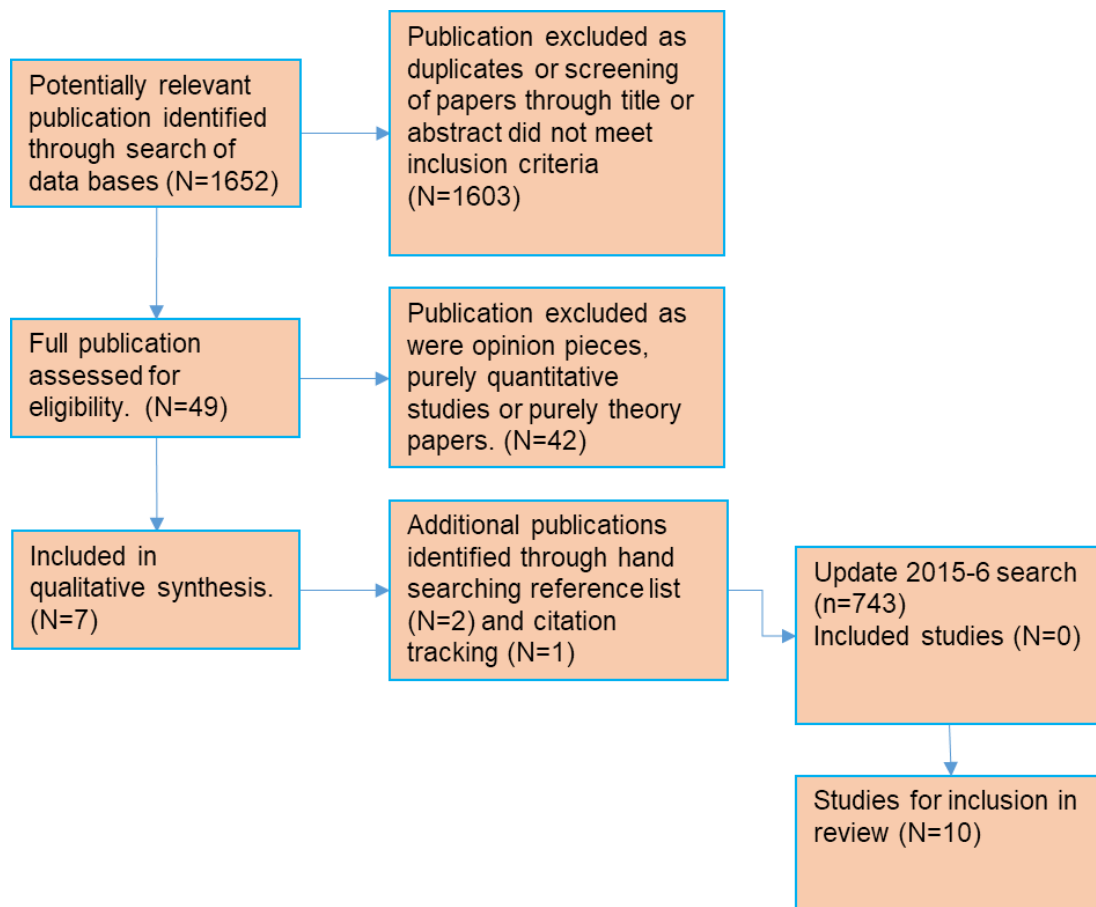
Quantitative studies were excluded as were mixed-method studies if it was not possible to retrieve free text data. Non English-language papers and 'grey' literature were excluded due to the time and cost that would be required to extend the systematic review to include these.

## **4.3 Quality appraisal**

There is considerable debate on whether or not concepts such as validity and reliability apply to qualitative research and if so, how these could be assessed (Hannes, 2011). Cochrane methodological guidance for qualitative methods involves (i) filtering against minimum criteria, involving adequacy of reporting detail on the data sampling, collection and analysis, (ii) commenting on technical rigour of the study elements indicating methodological soundness, and (iii) paradigmatic sufficiency, referring to researchers' responsiveness to data and theoretical consistency (Hannes, 2011). However, some authors consider that formal appraisals of quality may exclude some studies ranked as 'lower' in terms of technical markers of quality, but ratings may not be sufficient to invalidate the findings (Sandelowski et al., 1997; Jensen and Allen, 1996). To maximise the inclusion and contribution of a wide number of studies, a low-quality threshold was set using Dixon-Woods et al.'s five-point checklist for quality (Dixon-Woods et al., 2005). Research was included regardless of quality due to the difficulty of assessing this among studies which used a wide range of methods. The overall quality of papers was high (Table 3) supporting the robustness of the synthesis and findings. The lowest score, which was allocated to one paper, was 3.5/5 and five out of the 10 papers scored 5/5.

## 4.4 Findings

A total of 2,395 records, titles and abstracts were screened for inclusion in the review, of which 2,346 were excluded as they were either duplicates or did not meet the inclusion criteria, leaving 49 articles remaining. Of these, 42 were excluded once the full article was assessed for eligibility, as they were either purely quantitative papers, mixed-method studies where the results could not be separated, or opinion pieces, leaving seven articles for inclusion in the review overall. A hand search of the reference lists identified two further studies and another was identified through citation tracking. Thus the total number of studies selected for the narrative synthesis was 10 (see Figure 2 below).



**Figure 2 to show flow of articles selected**

## 4.5 Data extraction and synthesis

Three studies were from the USA, two from the UK, one from Canada, one from Bangladesh, two from Brazil and one from Jamaica. Topics covered by the studies are discussed in the narrative synthesis. Table 3 summarises findings from the 10 papers. In the studies women were interviewed retrospectively and contemporaneously, and some narratives were gained through repeat interviews. Table 4 summarises themes and sub-themes identified during the narrative synthesis using the OSOP (one sheet of paper) method (Ziebland & McPherson, 2006).

Each paper was allocated a number. Other table headings included author, country, method, sample type and size and key findings, and a quality score for each paper (see Table 3). Themes were extracted and adjusted, merged or excluded using the principle of the constant comparison method and OSOP technique (Ziebland and McPherson, 2006; Strauss and Glaser, 1967) by the first reviewer WC with full text papers (see Table 4).

Contradictions and relations between the themes were explored before a final list of themes and subthemes were agreed by discussion and consensus of all of the reviewers (JS, DB, NM) using the OSOP method to visually map out themes and subthemes (Ziebland and McPherson 2006) (see Table 4).

Table 3: Characteristic of included studies						
Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality Scores
1	Brewer et al 2014 USA	To evaluate the extent to which The Pre-eclampsia Registry responded to narrative inquiries and to ascertain the depth of information related to patient education. Online USA.	Online open-ended questionnaire with free text format included for one question about patient education.  Retrospective questionnaire.	807 participants, 301 provided a response for a total of 355 pregnancies.	Additional information for women with pre-eclampsia was identified by 241 participants:  Themes identified included:  Symptoms Definition of preeclampsia Improved provider communication Risk factors for preeclampsia Postpartum preeclampsia Closer monitoring Psychological support Complications Dietary concerns	5
2	Harris et al 2014 UK	To investigate the potential psychological impact of providing pregnant women with formal risk information for an antenatal screening test for pre-eclampsia. One London NHS trust.	Cross-sectional semi-structured interview study of women who had first trimester pre-eclampsia screening test.  Retrospective interviews at 16 weeks gestation.	15 primigravida women, who had high risk results and 5 with low risk results at 12 week pre-eclampsia screening	Two types of coping typologies regarding risk information for pre-eclampsia;  <b>'Danger Managers'</b> who were focused on risk that pre-eclampsia posed to them and exhibited information seeking, positive behaviour changes and cognitive reappraisal coping mechanisms.  <b>'Fear Managers'</b> who had an external sense of control and focused on the risk that pre-eclampsia posed to the foetus and exhibited avoidance coping mechanisms.  3 others themes emerged: medicalising pregnancy, embracing technology and acceptability.	4.5

Table 3: Characteristic of included studies ( <i>continued</i> )						
Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality Scores
3	You et al. 2012 USA	To explore the extent to which pregnant women understand the symptoms and potential complications related to pre-eclampsia and to determine the factors that are associated with better understanding.  A university clinic in USA	Face to face survey with one open-ended question with free text.	Convenience sample of 112 women recruited between 18 and 40 weeks gestation. 110 completed survey.	The survey identified a poor understanding of preeclampsia with a knowledge deficit. Factors associated with a greater understanding of preeclampsia were higher literacy, multiparity, history of preeclampsia, a receipt of information about preeclampsia from a clinician or another source.	5
4	Vasconcelos de Azevedo et al 2011 Brazil	To understand the meaning of preeclampsia for pregnant and postpartum women and healthcare professionals  Antenatal clinic and admissions unit of a public maternity hospital	Word association test and semi structured interviews.	51 pregnant women, 10 postpartum women, 87 health professionals completed word association test.  18 women, 2 postpartum women and 20 health professionals were interviewed.	Thematic categories based on word association test and the interview were created to help the data analysis. The results together demonstrate that pregnant and postpartum women had no information about preeclampsia.  The meanings of preeclampsia to pregnant and postpartum women were fear, risk, care and late of information.  For health professionals the meanings were care, fear, risk, high blood pressure, oedema and proteinuria.	4.5

Table 3: Characteristic of included studies ( <i>continued</i> )						
Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality Scores
5	Barlow et al., 2008 UK	To document women's experience of admission to hospital with a pregnancy related complication, hypertension from their own perspective  One UK maternity inpatient ward	Qualitative descriptive study, semi-structured contemporaneous interviews with women after sudden and unexpected admission with high blood pressure, and for some additional symptoms such as proteinuria and oedema.	12 women, two with diagnosis of pre-eclampsia at time of interview.	<p><b>Search for meaning:</b> 7 women had not noticed signs and symptoms and some felt frauds being admitted.</p> <p>5 women had noticed not feeling well, reduced fetal movements and two had had previous pre-eclampsia and were anxious and uncertain.</p> <p><b>Attribution to causality:</b> Some felt they had tried to relieve stress in their lives, so could not understand why their blood pressure had been raised, others described stressful events and felt this may have contributed to admission.</p> <p><b>Information needs:</b> Women valued being told the truth about their care pathway with diagnosis but some women felt they were not given enough information and were reluctant to ask staff questions. They reported being anxious and scared. Inconsistent information from different staff members was noticed.</p> <p><b>Social factors:</b> All women felt it important to have the support of their partner/husband and other family members. Seeing women go the delivery suite and to return with a healthy baby was reassuring whereas seeing women return for a caesarean with catheters and drips was seen as "scary".</p>	5

Table 3: Characteristic of included studies ( <i>continued</i> )						
Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality Scores
6	Kalim et al., 2007 Bangladesh	To assess differences in knowledge and care seeking behaviour in two districts of Bangladesh: Jessore, a high performing district of the country with higher literacy levels and lower maternal mortality ratio in comparison to Sylhet, a lower performing district of the country.	Mixed qualitative methods including free listing, rating exercises, hypothetical case scenarios and in depth interviews exploring the most commonly perceived complications, their relative perceived severity, knowledge of about signs and symptoms, care seeking behaviours related to PPH and eclampsia.  Retrospective interviews at unknown time limit after event.	118 women in total partook in studies, 40 regarding danger signs and care seeking for preeclampsia.	For women in low and high performing districts performing districts identified both PPH and eclampsia as life threatening complications.  <b>Understanding and knowledge;</b> In both districts women appeared to have a basic understanding of how to treat complications and where and were to take women for treatment, however, in real life case studies there were major differences between their understanding to the conditions and care-seeking behaviours in response to both PPH and eclampsia which could contribute to the high rate of maternal deaths associated with both conditions.  <b>Social and economic disparities affecting help-seeking behaviour;</b> There were differences in care seeking practices in the two districts possibly reflecting social cultural differences, disparities in economic and educational opportunity, and discrimination in the availability of care.	4

Table 3: Characteristic of included studies ( <i>continued</i> )						
Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality Scores
7	Lima de Souza et al., 2007 Brazil	To analyse maternal experiences of pre-eclampsia pregnancy with premature birth at a neonatal intensive care unit.  State hospital specialising in high risk pregnancies Brazil.	A qualitative study using focus group technique of women who had experienced pre-eclampsia with a premature birth.  Retrospective focus groups whilst babies were still inpatients.	28 women who had experienced pre-eclampsia in pregnancy with a premature birth.	<p>Themes included information on preeclampsia during prenatal care, experiences with a child in NICU, mother's perception of NICU professional attitudes.</p> <p><b>Information about pre-eclampsia:</b> it emerged from interview that women were unaware of pre-eclampsia which may have contributed to deficient preventative care and even to early hospitalisation. They only became aware after hospitalisation or by imminent premature delivery. Women feared their death or of losing their child.</p> <p><b>Mothers experiences with a child in NICU;</b> First visit was often associated with shock, sadness and despair. During NICU daily routine difficulties were reported on not being able to hold child and seeing intensive treatments. Conflicts arose between home and hospital activities. Women also discussed joy of bonding with the child when first held their babies and when phototherapy and IV tubes were removed.</p> <p><b>Mothers perceptions of NICU professional attitudes;</b> Difficulties were identified regarding caring for the child in the neonatal care unit accentuated by communication flows between health professionals and users.</p>	5



Table 3: Characteristic of included studies ( <i>continued</i> )						
Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality Scores
8	MacGillivray et al., 2004 Jamaica	To assess the efficacy and acceptability of a patient held pictorial card aimed at raising awareness and appropriate health seeking behaviour response to prodromal symptoms of imminent eclampsia.  Antenatal clinics in Jamaica.	Survey and contemporaneous and retrospective unstructured face to face interviews with staff and eclampsia cases postnatally. Time scale not given when interviews took place.	192 mothers were surveyed before distribution of maternal pictorial card with preeclampsia symptoms, and 134 after. 3 women were interviewed who had eclampsia after card distribution.  18 healthcare workers were interviewed in five antenatal clinics and obstetric team in a hospital.	Survey showed a mother's awareness and response to symptoms improved significantly with use of pictorial information cards, posters and education of signs and symptoms of pre-eclampsia and there was a significant drop in eclampsia incidence.  Post education programme there were 3 cases of eclampsia noted:  <b>Case 1</b> had not received the card at her antenatal clinic and had not seen a poster.  <b>Case 2</b> had a card and recognised the symptoms but went to her community health neighbour next door, delayed going to hospital and convulsed.  <b>Case 3</b> was a young teenager who reported symptoms to the high risk clinic but was told to bed rest and return again in one week. At the time the conditions of the referral hospital were overcrowded.  Interviews with healthcare workers identified that they felt the card had enabled mothers to recognise symptoms that should be acted upon and had the unexpected benefit of giving a focus for discussion when the healthcare workers saw mothers in the antenatal clinic as well as improving their own knowledge of when to act.	4.5

Table 3: Characteristic of included studies ( <i>continued</i> )						
Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality Scores
9	Harrison et al., 2003 Canada	To examine women's experiences of and satisfaction with their involvement with healthcare decisions during a high risk pregnancy.  A Western Canadian city.	In depth open-ended semi-structured interviews one month after birth with women who had experienced hypertension or threatened preterm delivery.	47 women; 16 women received at-home care through a community programme, 15 hospitalised care and 16 women with at-home care for index pregnancy and in-hospital management of a previous pregnancy.  26 women had pregnancies threatened by preterm delivery, 17 had hypertension and 4 had hypertension and preterm delivery.	Women felt an increased feeling of responsibility for the health of their baby and themselves. They exhibited two approaches to decision making: active partners and passive involvement.  <b>Women who wanted active involvement;</b> achieved it through one of 3 processes: struggling for, negotiating or being encouraged.  <b>Women who wanted more passive involvement;</b> women facing health crisis used the process of trusting the experts of nurses and physician.  Women were satisfied if the care from the health professional was congruent with how they wanted to be involved in decision making.	5

Table 3: Characteristic of included studies (continued)						
Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality Scores
10	Kidner et al., 2003  USA	To describe the experience of mothers whose pregnancies were complicated with HELLP syndrome and to determine if such experiences could be clustered by common themes from which a model could emerge.  USA, home telephone interviews in urban and rural settings.	Descriptive home telephone interview  qualitative study of survivors of HELLP syndrome  Retrospective interviews at 15 months to 13 years post-delivery, with 2 years being the mean.	9 self-selected survivors of HELLP syndrome.	<p>Participants expressed a loss of control and now knowing. 5 themes were identified; premonition, symptoms, betrayal, whirlwind and loss.</p> <p><b>Premonition</b>; Just feeling something was not right.</p> <p>Symptoms; symptoms described as back pain, fatigue, not feeling well, shortness of breath, abdominal. Pain, vomiting, severe upper quadrant pain.</p> <p><b>Betrayal</b>; women reported being led astray and deceived and having their concerns viewed as worthless. They reported a sense of betrayal for trusted women, healthcare providers and their own bodies.</p> <p><b>Whirlwind</b>; with recognition and diagnosis of HELLP syndrome physicians initiated an intensive whirlwind of activity to save mother and baby.</p> <p><b>Loss</b>; loss and grief caused by HELLP syndrome delivery that was so different from the expected pregnancy outcome.</p> <p>Emotions expressed were fear of death, frustration, anger and guilt.</p>	5

**Table 4 Summary table of themes and sub-themes**

<b>Theme</b>	<b>Subtheme including the paper where data was retrieved</b>
<b>Theme 1:</b> Women's knowledge and understanding of pre-eclampsia	Knowledge (1, 3-8)
	Absence or not recognising signs and symptoms (2, 5, 8-10)
	Range of information needs (1-3, 5, 8, 9)
<b>Theme 2:</b> Factors affecting help-seeking behaviour from perspectives of women and their families'	Emotions affecting help-seeking (2, 4, 5, 7, 10)
	Social, cultural and economic disparities (6, 9)
	Social networks influencing help-seeking (5, 6, 10)
<b>Theme 3:</b> Factors affecting staff response	Practitioner-client communications and relationship (1, 4, 5)
	Not being taken seriously (4, 8, 10)

## 4.6 Narrative synthesis

### Theme 1: Women's understanding and knowledge of pre-eclampsia

#### ***Subtheme 1: Knowledge***

A common finding was that many of the women who participated in the included studies did not have an understanding of pre-eclampsia or its implications for their own or their babies' health. Many were also unaware of signs and symptoms of pre-eclampsia until after their initial diagnosis (Brewer et al., 2015; You et al., 2012; Vasconcelos de Azevedo et al., 2011; Kalim et al., 2009; Lima de Souza et al., 2007; MacGillivray et al., 2004;). It was unclear if these women had any specific symptoms or signs and their lack of knowledge meant they did not appreciate the significance of these, or if they did not actually have any early warning of onset.

*"I didn't know. During prenatal care the doctor told me to rest and not to eat salt but she didn't say my pregnancy was high risk" (Lima de Souza, 2007 p.3)*

A lack of knowledge of pre-eclampsia among women who developed the disorder was reported in studies from several countries, including Brazil, Bangladesh, USA and Jamaica. For example, all of the 61 women interviewed in Vasconcelos de Azevedo et al.'s (2011) study from Brazil of the meaning of pre-eclampsia reported that they received almost no information about the disorder during their doctor's appointment or during the period that they were hospitalised. Women reported that they wanted to know more about the development of pre-eclampsia, how to avoid it, and the consequences of the disorder. A second study from Brazil reflected these findings in cases where women who had had a preterm birth as a consequence of pre-eclampsia were unaware of the pre-onset of the disorder. It was postulated that this may have contributed to deficient preventative care and to early hospitalisation caused by the severity of their condition (Lima de Souza et al., 2007).

There were similar findings in the UK: for example, women in a study from Warwickshire, which included 12 women, reported that admission to hospital had been sudden and unexpected following a routine antenatal clinic appointment due to high blood pressure and hypertension, and some had additional symptoms such as proteinuria and oedema (Barlow et al., 2008). This was also reported in studies from Brazil and the USA (You et al., 2012; Lima de Souza et al., 2007), further highlighting women's limited awareness of the signs and symptoms of pre-eclampsia.

Although most included studies highlighted a lack of understanding of pre-eclampsia or awareness of possible symptoms and signs, previous personal experience of pre-eclampsia was an important influencing factor. Barlow et al. (2008) in a study from UK found that two out of the 12 women-interviewed had pre-eclampsia in previous pregnancies and as a consequence were aware of symptoms and signs in the index pregnancy, which led them to self-refer for medical assessment and hospital admission by the process of early recognition and seeking professional help. The impact of having had pre-eclampsia in a previous pregnancy was also identified in the study in Brazil; however, this knowledge resulted in a subsequent fear of the disease. The study did not specify if previous experiences and knowledge had altered women's help-seeking behaviour (Vasconcelos de Azevedo et al., 2011). The quote below from a woman who had had pre-eclampsia previously highlighted the fear the women experienced:

*"I am afraid, I am afraid of having it again (pre-eclampsia)...it's because after the pregnancy I didn't have any high blood pressure problem, but then now on my second pregnancy I'm having it all over again (high blood pressure)..."* (Vasconcelos de Azevedo, 2011 p.184).

### ***Subtheme 2: Absence of or not recognising signs and symptoms***

The synthesis identified that women's lack of knowledge may prevent them from seeking timely and appropriate medical support due to a lack of awareness of pre-eclampsia and its implications ( Harris et al., 2014; Barlow et al., 2008;

MacGillivray et al., 2004; Harrison et al., 2003). However, another finding includes women who did not notice the onset of symptoms and signs of pre-eclampsia which may have 'prompted' them to seek help. Barlow et al. (2008) found that seven of the 12 women in their study did not notice symptoms or signs at all and consequently felt 'frauds' when they were admitted as an in-patient and took up a hospital bed, as the following quote illustrates.

*"I was in shock and upset that I had to come in. The only thing I know is that I've got high blood pressure and protein and something in blood. It's to do with pre-eclampsia, but I didn't understand what this is cos I'm fine in myself and the baby's fine... and you're thinking why can't I go home?" (Barlow et al., 2008 p.161)*

Some women had difficulty differentiating between common pregnancy symptoms such as nausea, vomiting, heartburn and oedema, and the early symptoms and signs of pre-eclampsia. Clinical staff also had similar problems (Barlow et al., 2008; Kidner, 2004). In two studies, women reported feeling that 'something wasn't right', with fatigue, not feeling well, shortness of breath, abdominal pain, nausea and vomiting, and severe right upper-quadrant pain and reduced fetal movements all reported as symptoms and signs experienced by women questioned in the studies (Barlow et al., 2008; Kidner, 2004). The quote below was from a woman who experienced symptoms and signs of pre-eclampsia but did not seek help.

*"I had everyone in the world, who was wiser than me, telling me that this was heartburn, that this was reflux, that this was stomach problems, that this was tensions I actually let the pain go unchecked" (Kidner, 2004 p.48).*

### **Subtheme 3: Range of information needs**

The studies selected for synthesis generated little insight into what information women needed, or when or how they would like to receive information. In four of the included studies women would have liked more information on pre-eclampsia (Barlow et al., 2008; Brewer et al., 2015; MacGillivray et al., 2004; You et al., 2012). In the study from Jamaica, there was a marked decline in the incidence of

eclampsia six months after women were offered information on what symptoms and signs to look out for, using pictorial cards, posters and antenatal education (MacGillivray et al., 2004). The authors considered that the intervention resulted in an improvement in the women's awareness of the importance of action concerning particular symptoms and of response to clinical advice in general. It also had the unexpected benefit of providing a focus for discussion when the healthcare workers saw the women in the antenatal clinic. The study also appeared to have resulted in an increased awareness among healthcare professionals of the prodromal symptoms of eclampsia, reminding midwives of important symptoms and signs to look out for and treat (MacGillivray et al., 2004).

Of note is that not all women in this study were supportive of use of the pictorial card. Younger women in particular felt the card was not relevant to them as it depicted an older woman (MacGillivray et al., 2004).

Only one study reported that women searched the internet for more information regarding pre-eclampsia (Harris et al., 2014). This was generally after women had a high-risk screening test result for pre-eclampsia. Some of the women used the information to consider how pre-eclampsia would affect them and wanted to know how to prevent it from developing, whereas others were more selective of the information. Since the original narrative synthesis was accepted for publication there have been a number of further studies highlighting women routinely using the internet for information.

One UK study which had conflicting results explored the psychological impact of providing women attending two maternity hospitals with risk-screening information for pre-eclampsia in the first trimester of pregnancy, with conflicting results (Harris et al., 2014). Although the majority of the women felt that if they knew they were at increased risk of pre-eclampsia they would have the advantage of being more likely to recognise the onset of the disorder, a minority questioned the usefulness of providing information for a condition that they perceived had no treatment and would increase their anxiety without providing a clear benefit (Harris et al., 2014). These findings supported those of the earlier study by Harrison et al. (2003)



in Canada who found that some women struggled to get the information they needed to participate in decision-making. Other women were satisfied with passive involvement in decision-making and wanted to trust the experts, perceiving healthcare professionals as having current and specialised knowledge that would be beneficial for them and their expected infant as the following quote illustrates.

*“If Dr M told me I had to stand on my head every morning for 10 minutes, I would do it. I would just do what she would tell me to do... they (doctors) are a lot smarter than me.” (Harrison, 2003 p.112)*

The amount of knowledge required was affected by women’s individual attitudes; an emerging finding was the impact of the women’s emotions on help-seeking once they noted symptoms and signs of pre-eclampsia. This is discussed in the theme below.

## **Theme 2: Factors affecting help-seeking behaviour from perspectives of women and their families’**

### ***Subtheme 1: Emotions affecting help-seeking***

Feelings and emotions were also found to alter women’s help-seeking behaviour and the amount of information they required. Fear was reported as affecting behaviour in five included studies (Harris et al., 2014; Vasconcelos de Azevedo et al., 2011; Barlow et al., 2008; Lima de Souza et al., 2007; Kidner, 2004).

Vasconcelos de Azevedo (2011) found that women who were afraid of the disorder and were aware that they and their infants could be in danger as a consequence, knew they needed to seek urgent medical care. The women wanted to be listened to and needed to understand what was happening to them. Kidner et al. (2004) identified that women experienced not only fear but also anger, and that women felt frustration during their efforts to seek relevant and timely information, as one woman explained.

*“I got frustrated with the physician. I was so frustrated I ended up crying at the doctor’s office because I was full of frustration and not feeling very well” (Kidner, 2004 p.50).*

In Barlow et al.'s (2008) study three women reported being anxious and scared; one woman had written a list of questions but was too upset to ask them. Another woman felt the doctors used big words or provided conflicting information as “*one says one thing and another says another*”. Here the perceived power imbalance between the healthcare professional who used complicated medical language and the woman, affected her ability to secure an appropriate response for their concerns.

### ***Subtheme 2: Social, cultural and economic disparities***

Other factors that affected women's and their families' help-seeking behaviour reflected social and economic disparities as reported in the study from Bangladesh (Kalim et al., 2009). In the 'low performing' Sylhet district (this is a term used to describe a district which has low literacy levels and a high maternal mortality ratio compared to other districts), family members first administered treatment in the home even after convulsions had started and only when these attempts failed did they consider hospital admission. This was in contrast to a 'high performing' district, Jessore, where family members called in medical assistance and transferred the woman to a health facility after the convulsing had started. Reasons proposed for these differences included cultural beliefs i.e. that eclampsia was associated with evil spirits, and structural barriers i.e. not being able to locate transport to take the woman to a health facility (Kalim et al., 2009). One respondent in Sylhet said:

*“Dushi (evil spirit) turns on a pregnant women if she stays outdoors in the early morning, in the evening, and at noon, ignoring rules, and heavy bleeding occurs in this case”* (Kalim et al., 2009 p.161).

The study's authors did not include quotes describing pre-eclampsia symptoms and signs but in three cases, the women's family members brought blessed water from a *huzur* (spiritual healer) as they believed that the *dushi* was the reason for the convulsions.

Other sociocultural differences were identified in the same study e.g. Sylhet women were less educated, making them more reliant on relatives, more conservative with a fear of male service providers possibly attending them in a health facility, and physical barriers including greater travel distances between the woman's home and the healthcare facility.

No other study specifically explored or compared impacts of social and economic disparities. In Canada, a woman's level of education was not associated with negotiation of participation in their healthcare decisions or with their level of satisfaction with their involvement in decision-making (Harrison et al., 2003). It is possible the USA, UK, Brazil and Jamaica had socioeconomic disparities which did affect help-seeking; however, it was not possible from the studies synthesised to identify differences in comparing women/healthcare professionals' accounts from these perspectives.

### ***Subtheme 3: Social networks influencing help-seeking***

Three papers identified the influence of women's social networks on help-seeking behaviour (Kalim et al., 2009; Barlow et al., 2008; Kidner, 2004). Although positive emotional support was recognised (Barlow et al., 2008), the potentially harmful influence of friends and family was also cited i.e. some women received false reassurance after seeking advice from other women regarding symptoms and signs (Kidner, 2004). This was reflected in the advice provided by a relative of a woman from Jessore who had developed a headache prior to fitting.

*"Everything was going fine...my daughter-in law told me that she was having headaches after lunch. I told her to lie in bed and to rest. Five minutes later when I came back to the room, I found that she was having convulsions, and her legs and head became curved. We did not wait much longer and took her to the hospital just after this." (Kalim et al., 2009 p.165)*

## **Theme 3: Factors affecting staff response**

### ***Subtheme 1: Practitioner-client communications and relationships***

There were limited findings on factors affecting healthcare professionals' responses to women presenting with self-diagnosed signs and symptoms of pre-eclampsia, or their families'. Practitioner-client relationships were mentioned in some studies. In Brewer et al.'s (2015) online patient questionnaire in the USA, open-ended responses were collected from the question *"Is there any other information about this pregnancy that would be helpful to you?"* Improved provider communication was identified as one of the emergent themes from this question (Brewer et al., 2015). Desired areas for additional information included symptoms, definition of pre-eclampsia, improved provider communication, risk factors for pre-eclampsia, postpartum pre-eclampsia, closer monitoring, psychological support and complications, and dietary concerns (Brewer et al., 2015). Vasconcelos de Azevedo (2011) also identified a communication gap between women and health professionals with regard to their experiences of pre-eclampsia. For example, fear and risk were associated with the disorder for women, whereas healthcare professionals' main focus was framed in terms of physical treatment:

Women were reported as finding the divergence of opinion about their symptoms and signs among healthcare professionals confusing and conflicting (Barlow et al., 2008). Barlow et al.'s (2008) research highlighted the need for healthcare professionals to be consistent as crucial to enabling women's positive experiences of care. One woman noted that day and night shift professionals often provided inconsistent information. The quote below illustrates this issue:

*"I am fed up with it, cos they tell you different things...when I got brought in, they says you'll be in for a fortnight and you'll probably have the baby. And next breath....you'll probably have the baby in 2-3 days. Then everything is on a level, and they say, we want to keep you until 36 weeks now"* (Barlow et al., 2008 p.163).

Again there was little to inform why inconsistent information was offered to women, but factors such as the model of care provision, the workload of wards, or individual healthcare staff may have influenced the provision of information.

Subtheme 2: Not being taken seriously

In three papers some of the women questioned reported symptoms and signs of pre-eclampsia but did not receive what they perceived to be an appropriate response from healthcare professionals (Kidner, 2004; MacGillivray et al., 2004). An example of this was a young teenager who reported her symptoms to healthcare professionals during attendance at a high-risk pregnancy clinic, but was advised to take bed rest and return to the clinic after one week. She later developed eclampsia (MacGillivray et al., 2004). Nine women from the USA who had had HELLP syndrome with significant symptoms-did not automatically seek medical assistance from healthcare providers. Some asked other older, perceived-to-be-wiser women about their symptoms, who reassured them that they were normal. Others had then escalated their concerns to healthcare professionals, but again were told not to worry as their symptoms were perceived as normal or resembled common pregnancy ailments (Kidner, 2004). After diagnosis the same symptoms and signs the women had reported were acknowledged as important and dangerous indicators of HELLP syndrome. This left women feeling betrayed after the preliminary delayed recognition and diagnosis. Additionally once admitted, some women felt their symptoms were devalued and treated as normal characteristics of pregnancy (Kidner, 2004), as the following quote illustrates.

*"I spent most of the time between throwing up and arguing with the nurse. She was incredible! It was like something out of the movie or something. She was just standing there and hollering at me, saying things like, "You are not actually doing anything to help the pain go away, are you? I think you're bringing this on yourself. I have already seen how much Demerol they have given you and you shouldn't be in pain at all. There is no reason for it." I was just sickened and stopped talking all together."* (Kidner, 2004 p.48)

Here the woman reported that the healthcare professional not only ignored her attempts to raise awareness of her symptoms, but belittled her, which had the effect of preventing the woman voicing her healthcare concerns again.

Although specific examples were not provided, Vanconcelos de Azevedo et al.'s (2011) study highlighted that staff did not listen carefully to the women to

understand how they were feeling and usually only considered their own perceptions.

Only one study investigated reasons why healthcare professionals did not respond appropriately to a woman seeking advice regarding her symptoms. In MacGillivray's study, where a teenager was told to take bed rest and return again after one week, the doctor made his decision as the maternity ward was running over capacity (MacGillivray et al., 2004). Here it is possible this could be compared to the SLB Theory where the woman's care was compromised as the doctor used his discretion to send her home due to the busy unit (Lipsky, 2010), however, it is only one example and he did not elaborate further why he made this decision.

## **4.7 Discussion and implications of findings**

Only 10 studies were eligible for inclusion in the narrative synthesis, highlighting the limited amount of research available in this area. Furthermore in these studies there was limited evidence of healthcare workers' perspectives. Despite this, from the evidence considered in this synthesis, three main themes were identified: women's knowledge and understanding of pre-eclampsia and potential signs and symptoms of onset; factors affecting help-seeking behaviour from the perspectives of women and their families; and factors affecting healthcare workers' response.

The most dominant theme identified related to women's lack of information and understanding of pre-eclampsia, which affected their ability to identify pre-eclampsia. This is supported by other help-seeking theories, for example, many believe that the first step to seeking help is the identification of the symptoms of the disorder or illness (Hay, 2008; Kolk et al., 2003; Gijsbers Van Wijk and Kolk, 1997). Information or knowledge of signs and symptoms of pre-eclampsia could be applied to the first stage in the identification of candidacy i.e. the process by which individuals come to view themselves as legitimate candidates for particular services (Dixon-Woods et al., 2005). Many wanted information on signs and symptoms, and experienced being offered conflicting information by healthcare

workers as disempowering. The synthesis did not highlight why health workers gave conflicting information, suggesting further exploration is needed in this area.

The synthesis also identified that some women did not develop noticeable 'classic' symptoms or signs of pre-eclampsia or found it difficult to distinguish these from 'normal' pregnancy health i.e. 'normalisation' of signs and symptoms was also shown to affect help-seeking. This is an important finding as it raises questions about the scope for women and families to contribute to this process given so many were unaware of signs and symptoms. This was another important factor identified in the Symptom Perception Theory (Moller-Leimkuhler, 2002; Gijsbers Van Wijk and Kolk, 1997). It is also an example of how difficult it may be to assert candidacy when women found it difficult to distinguish signs and symptoms of pre-eclampsia. There is little research exploring what are perceived as 'normal' signs and symptoms of pregnancy and how best to differentiate between these and more serious symptoms and signs, which might indicate pre-eclampsia or eclampsia, which is an acute medical emergency.

An important finding was that only one paper linked socioeconomic disparities with help-seeking behaviour (Kalim et al., 2009) and pre-eclampsia. Other studies have identified the significance of literacy levels for help-seeking (Owolabi et al., 2008). The authors of a Belgian study suggested that those women at greater risk of severe pre-eclampsia were asylum seekers who did not receive adequate antenatal care as they were unfamiliar with the maternity system of the host country (Haelterman et al., 2003). In the UK, the findings of a recent perinatal mortality report were that women from non-white ethnic groups and women in the most deprived quintile had stillbirth and neonatal death rates twice those of white women and those resident in the least socio-economically deprived areas (MBRRACE-UK, 2016). The lack of findings in this narrative synthesis suggests this is an understudied area.

Another important finding is from the four included studies that identified the influence of a family member or partner on a woman's help-seeking behaviour (Kalim et al., 2009; Barlow et al., 2008; MacGillivray et al., 2004; Kidner, 2004).

This ranged from generalised emotional support (Barlow et al., 2008) to women seeking help from other women regarding signs and symptoms (Kidner, 2004) and receiving false reassurance, to women actually being prevented from getting urgent medical care needed (Kalim et al., 2009). The opposite was found in a qualitative organisational case study as part of the Birthplace in England research. Of 58 women interviewed regarding an escalation of care requirement, 14 reported speaking up in situations they felt to be urgent. The women also identified their relatives or support partners playing an important role in helping them to speak up (Rance et al., 2013) and illustrated how they can act as safety buffers by voicing concerns and pre-empting failures in care (Rance et al. 2013).

At times healthcare workers had difficulties differentiating what women reported as important and requiring urgent escalation of care. Although the research was limited some women described not having their healthcare concerns responded to appropriately in some situations. Help-seeking behaviour among women could also have been affected by their attitudes and emotions (Harris et al., 2014; Vasconcelos de Azevedo et al., 2011; Kidner, 2004; Harrison et al., 2003). In some cases emotions such as fear for their safety and frustration encouraged women to speak up (Vasconcelos de Azevedo et al., 2011; Kidner, 2004), whereas in other cases emotions such as anxiety and being scared overwhelmed their ability to ask questions (Barlow et al., 2008). In Barlow et al.'s 2008 paper the perceived power imbalance between the healthcare professional and the woman, and the medical language used, affected women's ability to secure an appropriate response to their concerns. Thus the role of emotions when seeking help with symptoms and signs of pre-eclampsia cannot be isolated without understanding the complex sociocultural nature of help-seeking. Other authors have identified multiple variables of help-seeking with reference to symptom perception (Cornally and McCarthy, 2011; Rickwood et al., 2005; Moller-Leimkuhler, 2002; Kolk et al., 2002; Gijssbers Van Wijk et al., 1997), but none has researched pregnant women and pre-eclampsia.



The women's emotions were also affected by the healthcare workers' behaviour supporting Nadler's (1987) definition of help-seeking as "a three-way interactive process that involves the recipient, the helper and the task or problem" (Nadler, 1987). Other studies also identified that women's attitudes and characteristics themselves affected whether or not they wanted to seek help (Harris et al., 2014; Harrison et al., 2003), for example, if they wanted to be passive or active in their own care pathways. These studies did not indicate how differing behaviour patterns affected speaking up about signs and symptoms of pre-eclampsia, but possibly those women who relied on the expertise of staff would be less likely to question a health professional's decision to discount her concerns. These findings appear to challenge policy assumptions that all women want to actively contribute to their safety. They also support the Candidacy Theory, where work is needed so that individuals can assert their candidacy in an interaction with a healthcare worker (Mackenzie et al., 2013b; Dixon-Woods et al., 2005).

Similar to the synthesis, other authors have identified that even with information, detection and experience of symptoms, this may not automatically lead to the patient seeking help, with many complex, psychological and social reasons for this (Leventhal et al., 2016; Scott and Walter, 2010; Martin and Leventhal, 2004; Kolk et al., 2003; Kolk et al., 2002; Moller-Leimkuhler, 2002; Gijsbers Van Wijk and Kolk, 1997; Leventhal et al., 1980). The Candidacy Theory also understands the complexity of help-seeking by identifying seven overlapping stages in the process of negotiating candidacy: identification, navigation, permeability of services, appearing at services and asserting candidacy, adjudications by professionals, offers of resistance and operating conditions (Dixon-Woods et al., 2005). Further research is needed to understand how these stages may be applied to help-seeking and pre-eclampsia.

## **4.8 Limitations of the synthesis**

The dearth of research in this area resulted in the inclusion of just 10 studies, which had a wide range of aims and methodologies. Mixed-method papers were

only included if they reported free text comments, although it was often unclear how researchers had analysed the free text. For example, You (2012) stated that patients' verbatim responses were recorded and independently rated as correct or incorrect by their obstetrician. Women at different stages in their pregnancies were included and the studies addressed a variety of research questions (some of which were quite different to the question asked for this synthesis), potentially shaping the nature of the findings. Capturing women's views retrospectively and contemporaneously, or narratives gained through repeat interviews over time, may have impacted negatively on the synthesis.

There was no demographic or geographical restriction to selected studies, which were carried out in a number of countries with different healthcare systems, sources of funding and maternity care clinicians, making it difficult to compare results. The study settings included upper, upper-middle and lower income countries which could have affected synthesis of the findings e.g. the ability of an individual to pay for healthcare is likely to impact on help-seeking even when presenting with prodromal signs of pre-eclampsia. In addition, transport and access issues will vary across the countries.

A further limitation is that any review will be subject to the research available at the time and may be driven by the researcher's agenda rather than patient-informed priority (James Lind Alliance (JLA), 2013).

By analysing free text the aim was to capture the user and staff voice. However, by limiting the inclusion criteria to qualitative studies and mixed-method studies with free text, the scope of review may have been narrowed.

## **4.9 Conclusion**

This systematic review and narrative synthesis highlighted the paucity of research in this important area and raised a number of implications for future research. Further research is needed to establish what information is needed, and how and when women and their families would most benefit from it. The review confirmed

that this was an under explored area, with further investigation needed with respect to pre-eclampsia. A key finding of this review was that there was very little qualitative research available which explored how healthcare professionals' responses affected women's help-seeking when experiencing symptoms and signs of pre-eclampsia.

By applying help-seeking theories such as Symptom Perception Theory and Candidacy Theory, concurrence could be seen with help seeking behaviour from other researchers such as the importance of knowledge and normalisation. However, important differences were also acknowledged, with women and families experiencing symptoms and signs of pre-eclampsia i.e. understanding women's typologies, including those who want to be more involved in their care and those who want healthcare professionals to take responsibility, and how this affects their help-seeking behaviour, warranting further inquiry. There was a dearth of research available to understand what may affect negotiating in the healthcare service from the health workers' perspective, with only one paper giving reasons why safe care was compromised; Lipsky's Street-level Bureaucracy (SLB) Theory (Lipsky, 2010) may be useful to explore this further.

The findings from Chapter 2 and 3, as well as the systematic review and narrative synthesis in this chapter, were used to design the research methodology in Chapter 5. The gaps in knowledge helped guide the aims and objectives and how this data could be acquired.

## Chapter 5 Research Design and Methodology

The aims of this study are to understand the factors that influence (1) women and their families seeking help with early warning signs of pre-eclampsia and eclampsia, (2) healthcare professionals' response to these concerns, and (3) relationships between them.

The objectives of the study are:

- To identify the range of health concerns raised by women/partners/families, associated with signs and symptoms of pre-eclampsia or eclampsia during pregnancy, labour or the postnatal period, which require urgent medical attention.
- To identify the contextual factors i.e. information available, that influenced women/partners/families help-seeking when raising concerns with health professionals.
- To identify organisational, professional and social factors that influenced health professionals' ability to respond to the health concerns raised by women/partners/families.
- To identify strategies (e.g. information provided) in place to support women and their partners and families to raise concerns and health professionals responding to them and barriers and facilitators to their use.

The research design and methodology were informed by the literature review and narrative synthesis presented in Chapter 4 to increase understanding of how women, families and healthcare workers navigate their way through clinical uncertainty, risk and safety issues pertaining to experiences of pre-eclampsia during or after pregnancy.

This chapter presents a critical perspective of the context, the origins and the development of this research project, the rationale for the principles of a narrative methodology approach chosen, and an overview of the ontological and epistemological assumptions informing the research. In addition, approaches to

study methods, data analysis, ensuring study rigour and ethical issues including reflexivity, will be discussed.

## **5.1 Context, origins and development of the PhD project**

The topic of my PhD project is personal for me as one of my main aims in life is to reduce health inequalities and this was the reason I became a registered nurse and midwife and completed my Master's degree in Public Health (MPH). Over the last 20 years I have cared for patients in the UK and overseas with complex health and social needs. I have witnessed the many different factors that can affect access to care and the difficulties many patients' experience negotiating health services. As a clinician I am also aware of some of the barriers that may prevent appropriate healthcare responses being given.

The study follows on from my MPH research which used qualitative methods to explore teenage mothers' experiences and perceptions of quality and safety of care when there were complications in labour (Carter, 2010). Six teenagers were recruited from an inner-city teaching hospital and data was collected using semi-structured interviews. The findings identified four main themes that affected their care: expectations of care; stereotyping and stigma; being heard and informed; and different types of responses to an emergency (Carter, 2010). This study contributed to the case studies which were part of the Birthplace in England research on this issue. These studies highlighted the need for further exploration of factors that affect the experience of women and their partners/families who have concerns about their health in a complex organisation such as the NHS. For example, Rance et al. (2013) highlighted that 'speaking up' was no guarantee of women or their families being listened to, or having an appropriate response from a healthcare professional (see Chapter 1). Thus by understanding more fully the role that women, partners and families play when health events occur, there is the potential to intervene earlier, or to prevent some of these adverse events.

## 5.2 Rationale for methodological approach

The empirical research was informed by a qualitative design, an approach suitable to understanding more about a phenomenon rather than to measuring it (Green and Thorogood, 2009). The research question, aims and objectives required a methodology able to explore and understand why people do things and to explore and understand their interpretations of events and actions (Berger and Luckmann, 1967). Chapters 1 and 2 highlighted that there was a paucity of research and little understanding of what factors affect women and their families help-seeking with pre-eclampsia, and even less understanding of what factors affect healthcare workers responding; for this reason the principles of a narrative approach was selected. A narrative approach can be characterised as an analyses of stories, errors, near misses and adverse events, which can be processed and used as examples to change practice (Berlinger, 2003).

The word 'narrative' can be defined as “ a spoken or written account of connected events; a story”; however, when used in social research the term carries many meanings and is used in a variety of ways by different disciplines (Riessman, 2008). By using a narrative approach the object of investigation is the story itself, and the purpose is to see how respondents in the interviews impose order on the flow of experience to make sense of events and actions in their lives (Riessman, 2008). This process of actively constructing life stories is crucial to the understanding of clinical and therapeutic interactions (Liamputtong and Ezzy, 2005 p.135) and is appropriate as a means to create a greater understanding of women's experiences of perinatal care pathways for those who have had pre-eclampsia. In addition, it was beneficial to gain an understanding of the sense-making that staff engage with when recounting their experiences of working with women with pre-eclampsia in the perinatal period.

There are several different approaches to using narrative methods. Disciplines include those that assume that all narratives are stories about specific past events and have common properties. The most oft-cited approach is Labov and Waletzky's structural model of narrative form. These authors argued that narratives

have formal structural properties and that the patterns which recur in narrative can be identified and used to analyse each element of the account (Labov and Waletzky, 1967). Another narrative approach is influenced by phenomenology, which takes the position that the narrative constitutes reality, and that it is in the 'telling' that phenomena can be identified in the stream of consciousness (Riessman, 1993). Bamberg (2012) took this approach further and advocated that narratives are about people (characters), who act (events) in space and time, typically across a sequence of events (temporality). This view was similar to the Labovian approach which is event-centred in that it defines narrative in terms of the representation of events. It is also text-centred, in that it embodies an understanding of the personal experience narrative and takes little account of context (Patterson, 2013).

Some consider that results of narrative research may be narrow, idiosyncratic, or ethnocentric and that the participants tend to see the stories they tell as their personal experiences and these may not reflect on the society that has impacted on their lives (Yow, 2005 p.17). There may also be some limitations to using narratives as a succession of chronological events. No allowance is made for the inevitability of partial accounts and the constructed nature of any account of personal experience. Moreover, if one takes a strictly Labovian approach to some types of data, focusing solely on chronologically ordered past tense clauses, analysing them in isolation from the rest of the transcript, no account of the context in which the narrative was produced could result in overly simplistic, reductive analysis and interpretation (Patterson, 2013).

A third form of narrative approach, proposed by Plummer (1995), is where narratives are bound into a wider social world. He argued that stories can be used to maintain the status quo and have an emancipatory function which could affect individual lives and the wider culture (Plummer, 1995). An example would be the use of individual stories told by the less-powerful such as US slave narratives and the testimonies of peoples under occupation to represent the wider group (Plummer, 2001).

Understanding of the contribution of the wider social world in narratives was later represented in experience-centred to sociocultural-oriented approaches to narrative research. The experience-centred approach assumes that narratives are sequential and meaningful; are definitively human; represent experience, reconstituting it as well as expressing it; and display transformation or change (Squire, 2013). Researchers often explore how participants express improvement in stories and try to understand the stories (Squire, 2013).

To complement the narrative approach there was also a semi-structured component to the interviews. Here key questions were asked that arose from the systematic literature review, with some probing for further information where necessary (Arthur and Nazroo, 2007 p.111). The research presented in this thesis used an experience-centred approach as by analysing a participant's narratives in this way it was hoped that the social aspects of the stories may inform the wider management of pre-eclampsia care pathways, particularly in relation to women's ability to contribute to early recognition and response. Thematic analysis was used to interpret the data of the narratives as it is suitable for researchers interested in narrative themes, commonalities and differences across groups and individuals (Squire, 2013). Such stories may be event-narrative, but they may be more flexible about time and personal experience, and may be defined by theme rather than structure (Squire, 2015). An example of this approach was Squire's interview study of participants living with HIV in South Africa, where participants saw the interviews as a way of 'speaking out' for themselves and others (Squire, 2007).

In summary, the principles of a narrative approach were selected as an appropriate method for a number of reasons. Chapter 1 identified that the onset of pre-eclampsia can affect any pregnant woman unexpectedly; however, some groups of women are more at risk, for example, those with pre-existing disease at pregnancy commencement such as chronic hypertension, diabetes or obesity. Some ethnic groups and those of low socioeconomic status have an increased risk of pre-eclampsia, as do older and younger pregnant women (Berg, et al., 2009; Silva et al., 2008). A narrative approach can be used to help understand and unpick the



complex care pathways women experience and the wider influences of social life and social practice (Miller, 2000). It has also been recognised as a method which can enhance the understanding of professionals in order to engage with vulnerability and assist vulnerable people (Holloway and Freshwater, 2007b).

Some authors have recognised that a narrative approach can be used to deepen our understanding of the constitution and impact of social structures including age, socioeconomic position, gender and ethnicity (Bourgeault et al., 2013). It has also been suggested that by using analysis of stories, errors and near-misses, an adverse event can be processed and used as examples to change practice (Berlinger, 2003).

### **5.3 Ontological and epistemological approach**

Ontologies are beliefs about the basic entities that make up reality (Giacomini, 2013 p.129), while epistemology can be defined as a branch of philosophy concerned with 'knowing', including what the nature of knowledge is, how we come to know what we know and how we demonstrate the legitimacy of that knowledge (Green and Thorogood, 2009). Research into ontological philosophy ranges from realist to idealist (Giacomini 2013 p.129). Realists believe that the world possesses qualities both independent of our ideas and empirically accessible to us, in contrast to idealists who believe that we have direct access only to our ideas and subjective experiences and no empirical access to the world beyond, except through these ideas (Giacomini 2013).

The research question for this PhD required an ontological and epistemological position that reflected the need to study the many different and complex components involved, including the clinical condition (pre-eclampsia), the NHS organisation, and the perceptions and understanding of women, their partners and family members, and healthcare workers. By using the principles of a narrative approach the concerns identified in Chapters 1, 2, 3 and 4 could be addressed, namely, that there is little insight on the social determinants of health or the effects of contextual factors affecting health outcomes in pre-eclampsia research. For this

reason a study site was selected that served a diverse maternity population including women from different socio-economic, cultural and ethnic groups, parities and ages and healthcare workers who manage a range of needs from women with socially complex lives to women who have medical co-morbidities. It was important to acknowledge the role of perception and the existence of individual social reality, but there is the possibility that the social world can be understood by examining patterns and regularities (Bourgeault et al., 2013 p.439) i.e. by using previous theories and frameworks such as Candidacy Theory to see if patterns of help-seeking with pre-eclampsia concur with or are in contrast to the dimensions of the theory. It is recognised that individual variants of circumstances, views or experiences will be found in the research population, but generalisation can take place at the level of categories, concepts and explanations (Ritchie and Lewis, 2007 p.269).

## **5.4 Study rigour**

Rigorous quality research is trustworthy and can be relied upon by other researchers (Liamputtong and Ezzy, 2005). When considering the rigour and quality of this study, concepts such as generalisability, transferability, validity and reliability were considered, discussed below.

### **Generalisability and Transferability**

Generalisability refers to the study findings being based on a study sample which could be described as of relevance beyond the sample and context of the research itself (Ritchie and Lewis, 2007). In qualitative research there is much debate as to whether it is valid to draw wider inference from a single study depending on whether it had any reality beyond the context in which it was derived (Ritchie and Lewis, 2007). Furthermore, there is now a greater appreciation that use of qualitative and quantitative research methods in a single study can and should be part of the social researcher's tool kit (Snape and Spencer, 2007).

In qualitative studies, the term 'transferability' is often used in place of generalisability as it conveys that the theoretical knowledge obtained for quality research can be applied to other similar individuals, groups or situations (Liamputtong, 2013 p.26). Some believe that it is not an issue for qualitative research where the aims are to provide 'thick' descriptions, or to address particularities, rather than to provide typical accounts or generalisable findings (Green and Thorogood, 2014 p.250). Others argue that by highlighting sampling strategies and thick descriptions of the research setting transferability can be obtained (Chilisa, 2012).

For this study 'representational generalisation' was sought which is defined as the extent to which findings can be inferred to the population sampled (Ritchie and Lewis, 2007 p.268). To enhance representational generalisability, purposive heterogeneity sampling was used to select women, their partners and family members, and healthcare workers to interview. This research approach can lead to a greater depth of information from carefully selected cases (Teddle and Tashakkori, 2009). To create in-depth data, the principles of a narrative approach was used by complementing narrative interviews with a semi-structured component.

### **Reliability and Validity**

Reliability can be defined as the replicability of research findings whether or not they would be repeated if another study using the same methods or similar methods was undertaken (Ritchie and Lewis, 2007 p.271). In qualitative research, terms such as confirmability, consistency or dependability may be used in place of reliability, but all refer to the security and durability of the research findings (Ritchie and Lewis, 2007 p.284). Validity refers to the ability of the research to reflect an external reality or to measure the concepts of interest (Elliot, 2005) or the internal validity which is an interpretation of the truth of the interpretation (Green and Thorogood, 2014).

There are debates as to whether the terms reliability and validity are relevant to qualitative findings where the focus is shifted from measurement to description and

understanding (Elliot, 2005). Furthermore, the notion of validity can be problematic as the constructionist traditions work with truths that are socially situated and reject a positivist idea of fixed and essential truth (Green and Thorogood, 2014).

However, there is a growing belief that in qualitative research, validity concerns the extent to which the phenomena under study are accurately reflected, as perceived by the study population (Liamputtong, 2013; Chilisa, 2012; Sandelowski and Borroso, 2007). This is also known as interpretive validity (Sandelowski and Borroso, 2007). Following on from interpretive validity is theoretical validity which refers to the credibility of the researcher's interpretation (Sandelowski and Borroso, 2007).

In line with the two definitions above and the work of Riessman (2008), it is apparent that two levels of validity are important: the story told by the research participant, and the validity of the analysis (or story) told by the researcher. This is supported by Larsson et al. (2010) who proposed that validity can be established by using narrative methods if there are rich data in the narrative descriptions of the teller, and if interpretations are comprehensive, coherent and grounded in empirical data (Larsson and Sjöblom, 2010). Thus while presenting the findings, verbatim quotations from the participants will be presented after discussion of the findings to support the researcher's interpretations (Liamputtong, 2013). To prevent the researcher's own interpretations and views influencing the findings, attention was paid to where data contradicted or appeared to contradict the emerging themes, which is known as 'deviant case analysis' (Mays and Pope, 2000). This offered greater insight to the analysis and demonstrated an attempt by the researcher to ensure credible findings.

## **5.5 Methods**

A methodology was required appropriate to meet the research aims and objectives to explore and understand why people in certain situations react in certain ways and to explore and understand their interpretations of events and actions (Berger and Luckmann, 1967). To meet these requirements, the principles of a narrative

approach were used, as *“the goal in narrative interviewing is to generate detailed accounts rather than brief answers or general statements”* (Riessman 2008 p. 23).

Narrative interviews were completed, informed by a semi-structured component to explore: (1) women and their families’ perceptions and experiences regarding the development of pre-eclampsia, (2) healthcare workers’ perceptions and experiences of caring for women who develop pre-eclampsia, and (3) charity group representatives’ perceptions and experiences of pre-eclampsia onset. In the initial narrative interview participants were asked to tell their own story with as little interruption as possible (Hinton et al., 2010). This was followed by a semi-structured component which included questions arising from the systematic literature review and questions added during the course of the study as new issues emerged.

To select appropriate participants, purposive heterogeneity sampling was used, a method which can lead to collation of a greater depth of information from carefully selected cases (Teddlie & Tashakkori 2009). Critics of this approach describe that it contrasts to random sampling, which promotes generalizability of findings by minimizing the potential for bias in participant selection and to control for the potential influence of known and unknown confounders (Palinkas et al. 2015). However if random sampling, had been used, it could have been considered as a potential weakness as *“the power of purposeful sampling lies in selecting information-rich cases for in-depth studies”* (Patton 2002). Random sampling may not have provided the in-depth perspectives necessary to meet study aims and objectives. A recent review by Gentles et al (2015) concluded that purposive heterogeneity sampling is *“fraught with ambiguity and lack of clarity”*. In line with Gentles (2015) advice to mitigate the ambiguities of purposive heterogeneity sampling, the sampling process for this study is described below. Use of a purposive selection criteria were influenced by the study aims, which in turn were influenced by the relevant literature searches presented in the initial chapters of this thesis.

### **Site selection and access**

Data collection took place in one inner-city NHS trust with two birth units, a labour ward and an integrated midwifery-led birth centre. This site was selected as it served a diverse population including women from different socio-economic, cultural and ethnic groups, parities and ages. The unit was a tertiary referral centre which provided obstetric consultant-led care, and had a midwife-led birth centre, a homebirth team and healthcare specialists who managed a range of needs from women with social complexities to women with comorbidities as a result of complex medical problems. The trust had an annual birth rate of around 7,000 births.

### **Inclusion criteria and exclusion criteria**

Study participants included clinical and other relevant maternity staff, charity group representatives, women and partners/families who experienced pre-eclampsia in the index pregnancy, who were over 16 years old and did not have a serious mental health diagnosis, and healthcare professionals. Family representatives were chosen by the women as the person who was significant to them. Women were not excluded if they declined to nominate anyone.

### **Patient and Public Involvement**

Patient and Public (PPI) was an important part in the planning of this research and is recognised by the National Institute for Health Research (NIHR) in their INVOLVE briefing notes (INVOLVE, 2012). PPI is recognised by the James Lind Alliance (JLA) as an initiative for bringing together patients, carers and clinicians to prioritise uncertainties about the effects of treatments that they agree are the most important (James Lind Alliance, 2013). A literature review of PPI involvement in research which included data from 89 studies concluded that this can increase recruitment to research and is of particular value in qualitative research where participants are asked to share their view and experiences (Staley, 2009). The review also found that PPI can influence the research topics, direction of research,

project design and methods, recruitment and data collection, analysis and dissemination.

In this study, maternity service users were involved in the design of the study and the development of the interview schedule. They contributed to discussions about the study methodology and to preliminary analysis of the early findings. This was achieved by presenting the different stages of the research at meetings of the Maternity Services Liaison Committee at the study site, the National Childbirth Trust (NCT) and a PPI panel who discuss pre-term birth studies. The PPI panel was set up at the study site to form a partnership with clinicians and women and their families regarding pre-term birth research. PPI collaboration continued during dissemination of the final report to assess the credibility of interpretation of the findings. In addition, to strengthen interpretative rigour supervisors were consulted during the primary data analysis and findings were shared with a wide reference group including public and patients. Respondents were asked to clarify issues or events when needed.

## **5.6 Interviews with women and partners/family members**

The aim of these interviews, stage 1 of the process, was to identify what signs and symptoms of pre-eclampsia and/or health deterioration were experienced by women; the factors that influenced the women, their partners or family members' ability to raise their concerns with healthcare workers; and the response of the healthcare workers to their raised concerns. The findings informed the content of the interview topic guides for healthcare workers and the charity groups semi-structured interviews (see Appendix 3).

The purposive heterogeneity sampling method (see Section 5.5 Methods p 92) was used as women from a range of socio economic backgrounds and ethnicities are known to have different maternal outcomes despite universal healthcare (CEMACH 2009). Recent maternal reports have also highlighted how comorbidities can impact on outcomes (MBRRACE-UK, 2017., MBRRACE-UK 2015., Knight et al., 2014).

For this study it was important to select sufficient cases with maximum variation to identify common patterns that cut across variations (Palinkas et al. 2015). This contrasts with the grounded theory approach because a maximum variation sample is unlikely to reach data saturation (Strauss & Glaser 1967). Sample size in qualitative interview research does not strive for statistical power but more for the rich data in narrative description of the teller (Larsson and Sjöblom, 2010), with no agreement among researchers as to the adequate number of subjects to fully explore the topic. Embedded in the strategy was the ability to compare and contrast, to identify similarities and differences of help seeking among women with pre-eclampsia (Palinkas et al. 2015). Initially the aim was to select approximately 20 women and their partners or family members. It was hoped that approximately 10 partners or other family members would be recruited. The challenges of recruiting and interviewing partners/fathers has been recognised by other researchers (Rance et al. 2013.; Macfadyen et al., 2011., Sherr et al. 2006).

A priori sampling framework was constructed by the researcher to take into account the range of women with different experiences of help seeking with pre-eclampsia i.e. women of all parities, those from different socio economic backgrounds, ages, and ethnicities. In addition, half of the sample group selected had been classed as 'high risk' at their first antenatal booking appointment, and half were classed as 'low risk' at booking. As described earlier, there are several maternal risk factors associated with pre-eclampsia (Mostello et al., 2002). The concept of risk assessment in pregnancy is to decrease perinatal and maternal mortality by identifying those women at risk of an adverse outcome as early as possible, and referring them to timely and appropriate treatment (Stahl and Hundley, 2003).

The priori sampling framework was given to the research midwives to guide on who they approached for recruitment (Table 5). They initially accessed this information from the booking notes. Complex social history included those who spoke English as a second language, single parents, those unemployed and those who had difficulty with housing e.g. living with parents in absence of another alternative



Each time they approached the women they would communicate with the researcher to check on the numbers recruited in each sample group until heterogeneity had been reached.

**Table 5 Priori Sampling Framework for women**

<b>Demographic characteristics</b>	<b>Low risk women</b>	<b>High risk women</b>
BME	3	3
English as a second language	3	3
Women with a complex social history	4	4
Total	10	10

In total twenty-three women and five partners or other family members, as nominated by the women, were selected for interview. Targets informed by the priori sampling framework were reached for the women (Table 5). This included women with complex social histories, women with co-morbidities and women assessed as uncomplicated or at low risk at their pregnancy booking appointment (NICE, 2010).

The women's ages ranged from 20 to 41. They were from a wide range of ethnicities, social and economic backgrounds. All women spoke English, although for some this was their second language. The majority of the women were primigravidas. Ten of the 23 women were classed as at high risk at booking as a result of a twin pregnancy, chronic hypertension, diabetes, a kidney transplant or previous history of pre-eclampsia. Thirteen women were classed as 'low risk' at booking. Women's pregnancy gestation when pre-eclampsia was diagnosed included 14 women diagnosed between 37 and 39 weeks gestation, six between 34 and 36 weeks and three before 33 weeks gestation. Tables 6 and 7 show the socio-demographic characteristics of the study sample.

It was intended that at least 10 family members would be recruited. However, recruitment proved challenging and only half of this target was reached. All the women were asked if they had a family member who would like to participate, but only five were recruited. The family members interviewed included two of the women's mothers and three women's partners. In this case, although it was not in the original data collection methodology, three of the interviews were dyad interviews at the request of the interviewees. On two occasions, this was because there was no other room in the house to undertake the interviews due to the other family members sharing the house and once it was a woman's personal choice. Other researchers have recognised when there are few potential interviewees at times opportunistic decisions need to be made (Green

and Thorogood 2014 p 121). Table 6 and 7 show the characteristics of the women and family members interviewed. It can be seen that the priori sampling framework for women was reached, but only half the number of family members were recruited.

**Table 6 Demographic characteristics of women interviewed**

<b>Ethnicity</b>	<b>No of Participants</b>
Black British	6
Black African	1
White British	9
East European	3
West European	0
Asian	3
Mixed Race	1
<b>Age</b>	
20-25	2
26-30	5
31-35	12
36-40	3
41-50	1
<b>High risk / low risk at booking</b>	
High risk	10
Low risk	13
<b>Parity at booking</b>	
Primip	20
Multip	3
<b>Gestation at time of delivery</b>	
31-33 weeks	3
34-36 weeks	6
37-39 weeks	14
<b>Latest Educational qualification</b>	
GCSE/O level	9
Degree	7
Postgrad	7
<b>Employment status</b>	
Employed	19
Unemployed	4
<b>Civil status</b>	
Single	3
Living with partner	20
<b>English as first language</b>	
English as first language	17
English as second language	6
<b>Accommodation</b>	
Owner occupied	10
Privately rented	3
Council accommodation	10

**Table 7 Demographic characteristics of family members interviewed**

<b>Ethnicity</b>	<b>No of Participants</b>
Black British	1
Black African	1
White British	2
East European	0
West European	1
Asian	0
Mixed Race	0
<b>Age</b>	
20-25	1
26-30	0
31-35	2
36-40	0
41-50	2
<b>Latest Educational qualification</b>	
GCSE/O level	2
Degree	2
Postgrad	1
<b>Employment status</b>	
Employed	3
Unemployed	2
<b>Civil status</b>	
Single	1
Living with partner	4
<b>English as first language</b>	
English as first language	3
English as second language	2
<b>Accommodation</b>	
Owner occupied	2
Privately rented	1
Council accommodation	2

### **Data collection**

Data were collected from one-to-one narrative interviews with a semi-structured component lasting approximately one hour. The researcher used the principles of a narrative approach concurring with Mishler (1986) that one of the significant ways through which individuals make sense of and give meaning to their experiences is

to organise them in a narrative form (Mishler 1986 p. 118). He believed by using a narrative approach the respondents have more control of the interviewing process and are therefore more empowered (Mishler 1986 p. 118).

Interviewees were advised by the researcher that the interview would take between 30 minutes and one hour. By not having a fixed time this allowed the respondents to set the agenda and be able to tell their stories how they wanted to, but were also given a guidance as to how much detail to provide (Elliot, 2005 p 32). To facilitate the narrative interview an open ended introduction and a brief synopsis of the aim of the research was offered as it is recognised that respondents may be more likely to find it easier to talk about specific times and situations rather than being asked about a very wide time frame (Elliot 2005 p 31). See Appendix 3. The importance of being a good listener and not interrupting the interviewee's narratives was an important component in terms of the approach of the data collection and has been recognised as such by several narrative researchers (Riessman 2008, Elliot 2005; Mishler 1986).

To complement the principles of the narrative approach used there was also a semi-structured component to the interviews. Key questions were asked, informed by the systematic literature review and with some probing for further information where necessary (Arthur and Nazroo, 2007 p.111). This was also a useful tool to facilitate women and their family members responding who were less comfortable with the open ended opening narrative question (See Appendix 3).

The research site was a tertiary care centre with many research projects. This has been recognised as having a positive effect on recruitment, with researchers commenting that patients may be more likely to trust an invitation for research participation from a specialist centre (Newington and Metcalfe 2014). Women on the postnatal ward or attending postnatal community clinics were informed about the study by the research midwives and offered an information leaflet. Recruitment has been shown to be influenced by recruiters' professional roles, their personality and knowledge of the research project (Newington and Metcalfe 2014). The research midwives were well trained in recruitment methods and they all had in-

depth knowledge of pre-eclampsia as they were specifically assigned to a hypertensive research team. The research midwives also had the Prior Sampling Framework (See Table 5) to prevent the danger highlighted by Newington and Metcalfe's (2014) in their qualitative research where it was found that there is the potential for recruiters to stereotype potential participants based on previous experiences, and therefore choose not to approach individuals who are otherwise eligible i.e. by approaching women they think will say "yes" rather than approaching a range of participants.

If women were interested in participating, the research midwives asked if they could give the women's mobile phone numbers to the researcher to contact them to provide more information. Only two women who were approached by the research midwives declined to be interviewed following this approach.

Some believe a retrospective approach can lead to poor data as interviewees may have poor recall (Elliot, 2005, p 86) if the interviews took place up to three months after the birth. This was to enable the women to discuss their whole journey through pregnancy, the birth and the postnatal period and enable a sufficient time to pass since giving birth for the woman and her partner (if relevant) to have adjusted to family life.

## **5.7 Interviews with healthcare workers**

The aim of stage 2, was to identify the organisational, professional and social factors that influenced healthcare workers' ability to respond to the health concerns raised by women, and the role of strategies and practices to enable women to raise concerns and healthcare workers to respond. It was also to explore the healthcare workers' knowledge of signs and symptoms of pre-eclampsia, what would raise their concerns and what would prompt them to take action. The narrative synthesis (Chapter 4) highlighted a dearth of research in this area. Barriers and facilitators of healthcare worker's ability to respond were explored. The interview topic guide (see Appendix 4) was developed from findings from the literature reviews in

Chapters 1, 2, 3 and 4 and from themes that evolved from the women's and family members' interview data.

### **Setting**

Private rooms were booked for staff interviews in the hospital setting if they requested it and for some who wished to do their interviews in their home setting. Phone interviews were offered if requested.



## Participants and sample size

As with selection of women for interview, purposive heterogeneity sampling was used to select healthcare workers. Respondents who were most likely to yield appropriate and useful information were selected (Bourgeault et al., 2013). Initially the aim was to recruit approximately 8 midwives, 3 obstetricians, 2 care assistants/administration staff, and 2 managers. By interviewing a range of seniorities, from junior to senior staff, and job roles, different perspectives of social and organisational complexities were identified. In addition, by interviewing staff with different job roles i.e. staff from community, antenatal wards labour ward, early assessment unit, high-dependency unit, maternity help line and postnatal ward, further understanding was gained of staff perspectives on themes identified in the women's narratives. This included midwives representing Bands 6, 7 and 8. See Table 8 for priori sampling framework.

**Table 8 Priori Sampling Framework for health care workers**

<b>Characteristics</b>	<b>Obstetricians</b>	<b>Midwives</b>	<b>MSW</b>
Managerial position	1	1	
Senior	1	3	2
Junior	1	4	
Total	3	8	2

In total eleven midwives, four obstetricians and two maternity support workers were interviewed. Midwives representing Bands 6, 7 and 8 and senior and junior obstetricians were selected, including those in managerial roles. See Table 9.

## Data collection

Recruitment of staff participants was via an email invitation sent by the researcher, and subsequent 'snowballing'. Interviews took approximately one hour. The interviews were conducted in private hospital rooms or by telephone; one was at home. Staff were difficult to recruit; some said this was because they did not have time, and no other reasons were given.

After the initial email only two staff came forward. After snowball sampling two further doctors were interviewed. Further emails were sent, but with no response. The research midwives who had recruited the women for the study were then approached and asked for their help with recruitment of healthcare workers in a range of clinical settings. This was effective; 14 other healthcare workers were recruited. As with the women and family interviews they gave the healthcare workers the information leaflet for the study and the researchers' phone number if they were interested. Each was allocated an identification number from S 1 to S 17. See Table 9 below for participant characteristics.

### **Data collection**

Recruitment of healthcare worker participants was via an email invitation sent by the researcher, and subsequent 'snowballing'. This is where an initial respondent is asked to suggest other people who may be willing to participate (Liamputtong and Ezzy, 2005 p 47). Interviews took approximately one hour. The interviews were conducted in private hospital rooms or by telephone; one was at home.

Healthcare workers were difficult to recruit; some said this was because they did not have time, and no other reasons were given. For example after an initial email contact, only two staff came forward. One of these members of staff offered to ask their colleagues which resulted in two further doctors being interviewed. Further emails were sent, but with no response.

The research midwives who had recruited the women for the study were then approached and asked for their help with recruitment of healthcare workers in a range of clinical settings. This was effective; 14 other healthcare workers were recruited. As with the women and family interviews they gave the healthcare workers the information leaflet for the study and the researchers' phone number if they were interested. Each was allocated an identification number from S 1 to S 17. See Table 9 below for participant characteristics.

**Table 9 Demographic characteristics of healthcare workers interviewed**

<b>Job role</b>	<b>No of Participants</b>
Midwife	11
Junior Doctor	2
Consultant	2
Maternity support worker	2
<b>Age range</b>	
26-30	5
31-35	4
36-40	2
41-50	6
<b>Grade of job</b>	
Band 6 midwife	4
Band 7 midwife	6
Band 8 midwife	1
SHO	1
Registrar	1
Consultant	2
MSW	2
<b>Years of experience in NHS</b>	
0-2	2
3-4	3
5-10	5
10 +	7

## **5.8 Interviews with charity group representatives**

The charity group representatives approached and invited to participate (stage 3) included individuals linked with five charities, advocacy organisations and user groups who represented women who had pre-eclampsia and their partners/families. These included: Action on Pre-eclampsia (APEC), Maternity Service Liaison Committees (MSLC), National Childbirth Trust (NCT), Birth Trauma Association (BTA) and MAMA Academy.

The organisations represented a wide range of maternity service users and provided expert knowledge of social and medical complexities regarding pre-eclampsia. These representatives were involved to give an understanding of the scale and nature of the problem and provide a follow-up of the interviews from stages 1 and 2 (see Appendix 5 for topic guide).

## **Setting**

Interviews were conducted at a place and time convenient for the participant. This included their home or a private room in the community, hospital setting or in an office of the organisation. A telephone interview was also offered as an option.

## **Participants and sample size**

Five charity representatives were interviewed from organisations and user groups (listed above) who represented women and families who had pre-eclampsia. No specific demographics will be given as it would compromise their anonymity. Identification numbers were allocated from C 1 to C 5.

## **Data collection**

Topic guides were used which were informed by the narrative interviews with the women and their partners/families and healthcare workers (see Appendices 4, 5 and 6). The researcher used open-ended questions exploring stakeholders' perceptions of the scale and the nature of the problem and the factors that influenced it.

For women, family members and healthcare workers protecting their identity was seen as paramount. Anonymity and confidentiality were essential components of the research methodology and are seen as a core principle of ethical research. It is widely recognised that research should avoid disclosing information that would harm participants (Cresswell and Poth 2017, Kaiser 2009). See Ethics Committee documents, Appendices 8, 9, 10 and 11. See under heading "pseudonyms and profiling" below of how this was achieved.

## **Pseudonyms and profiling**

Protecting the participants identities was important for women their families, health workers and the charity representatives. "Anonymity" means the identity of those taking part not being known outside the research team and "confidentiality" means avoiding the attribution of characteristics of participants in reports or presentations

which could be used to identified patients (Ritchie and Lewis 2007 p 67). This could both be by direct attribution and indirect for example by referencing a collection of characteristics that might lead to the identity of the individual being recognised (Richie and Lewis 2007 p 67). For the women this could mean by documenting their age, ethnicity, risk factor and pre-eclampsia pathway, there was the potential that they could be identified by somebody that knows them. For healthcare workers this could be by documenting their job title and number of years worked. As a PhD is a published thesis it was decided not to create a tables with participant profiles as this would make it possible to identify individuals. It was important for the researcher to remove identifiers to create a “clean” data set (Kaiser 2009). This was particularly important given that the research may be presented to a variety of audiences, including members of participants’ communities (Crow and Wiles 2008).

Use of pseudonyms is also used to anonymise the participants and protect identities (Lahman et al. 2015). However, some researchers have concerns with allocation of pseudonyms, for example the inadvertent misuse of power by allocating someone else a name (Lahman et al 2015). Allen et al (2016) questioned *“what assumptions can be made about the age, gender, ethnicity, and socioeconomic status of the person each name represents, the intentions in the choice of name, and even the research project in which they might have participated?”* (Allen and Wiles 2016). Other researchers have taken it further and believe that where anonymization if used on women has been seen as a form of paternalism (Berkhout 2013, Crow and Wiles 2008) and some have taken it further and suggested that neither ethics committees nor informed consent strategies ensure ethical research, in itself, and suggest that by using pseudonyms the participants own history, knowledge and identity are captured (Svalastog and Eriksson 2010). These issues question the assumption that study participants want anonymity and highlight some of the difficulties involved in engaging with the use of pseudonyms (Crow and Wiles 2008). This presents researchers with difficult choices between respecting the preferences of those participants who wish to be identifiable and those who prefer to remain anonymous (Svalastog and

Eriksson 2010, Crow and Wiles 2008, Bradley 2007) .

Another concern is by using pseudonyms subtle clues may be provided to the identify of participants (Iphofen 2011). For example by giving an African participant and African pseudonym her identity could be inadvertently made public. Due to the concerns raised above the researcher allocated numbers rather than pseudonyms for all the participants and chose a cautious approach by not offering the participants the choice to select their own pseudonyms. As mentioned above participant profile tables were also not used for protect the identity of all the participants. None of the participants asked for their own names to be used and all were concerned about maintaining their identity anonymous.

### **Field notes**

During data collection i.e. when the interviews were being undertaken, field notes were hand written just after each interview, out of sight of the interviewee in a log book. Although field notes are typically used in ethnographic studies (Emerson et al. 2011 p 22), where researchers make notes, jottings and or audio-recordings of their observations and experiences in the field (Bourgeault et al. 2013 p. 364), they can also be a useful data source for narrative studies (Riessman 2008 p. 68). For this study although the interview data was captured through audio-recording the researcher also used field notes to record thoughts about the dynamic of the encounter (Ritchie and Lewis 2007 p 133). The researcher was selective what to write in the field notes rather than writing everything seen. It has been recognised that it is not possible to record everything in field notes as social scenes are inexhaustible (Hammersley and Atkinson 2009 p 144).

The field notes were written just after each interview, not in the presence of the interviewee, as the researcher did not want it to intrude on the relationship with the interviewee (Emerson et al. 2011 p 23). During the process of data analysis the field notes were also checked alongside the coding of the interviews, which were analysed on NVIVO.

## 5.9 Analysis

Interviews were taped and audio recordings transcribed verbatim. Field notes were handwritten in a field notebook before and after the interviews. The interview transcripts were imported and stored using NVivo 10 software.

The first stage was to read each transcript several times to get a sense of the individual's story (Gergen and Gergen, 1988). Subsequently short summaries of each of the women's pregnancy narratives were written down (see Appendix 7). The summaries linked each woman's risk status at booking (identified by the research midwives), their reflections on their emotions at the diagnosis, their experiences of signs and symptoms of pre-eclampsia, and their experiences of help-seeking. The summaries were an early indication of emerging codes and themes, and were stored on NVivo as 'memos'. This was useful when proceeding with the next step of data analysis.

Following this, the data were analysed using a combination of thematic analysis and constant comparison (Strauss and Glaser, 1967). Most approaches to thematic analysis involve familiarising with the data, coding the data set and organising codes and themes (Green and Thorogood, 2014). This method of analysis was chosen as the range and number of participants made other narrative analysis methods unsuitable.

NVivo 10 was used to sort codes and themes that emerged from the narrative thematic data analysis. The NVivo themes were derived directly from actual words in the narratives. This software is a suitable tool to compare themes across the data set and to highlight cases which do not fit with the emerging analytical pattern (Snow et al., 2013; Hinton et al., 2010).

Interviews were analysed initially in three stages: 1. the women and partners/families, 2. the health workers and 3. the charity participants, before combining the interview data sets for the final analysis. The healthcare workers' interviews explored additional factors identified from the women's interviews, for

example, organisational, professional and social factors that influenced the health worker's ability to care for and to respond to women with symptoms of pre-eclampsia. The PPI interviews gave an understanding of the scale and nature of the problem and were a useful follow-up of the interviews from stages 1 and 2.

Field notes was also used during data analysis. Two examples are shown below of the field notes and how they were used during data analysis.

For example for the three triad interviews the field notes were useful to see why these occurred i.e. in two situations it was because the accommodation where the interviews took place had no spare rooms due to a number of families residing in each of the properties. An example of the field notes can be seen for participant W 123 and P 124.

*"I entered the flat. It was very crowded. The mother's bed was the sofa bed in the sitting room. This was being put back up when I arrived. One baby was on the sofa, the other in a cot. Grandmother and grandfather were present. Grandfather left the room. I apologised. The interview was short. The grandmother also participated."*

Another example where field notes were useful to try and understand the interview data was describing the distress of one participant, who unusually did not hold the baby at all during the interview and had a nanny. I was concerned she had post-traumatic stress disorder and was having difficulty bonding with the baby. The interviewee did not mention this, but in the field notes the mother eluded to the impact of the experience after I had turned the tape-recorder off. After the tape was off the researcher recorded in the field notes that

*"W 111 said it had really scared her from having any more babies".*

It can be seen that although field notes are used traditionally during ethnographic studies, they were also a useful supplement to narrative interviews in this study.



## **5.10 Research governance and ethics**

### **Ethics**

Before applying for ethical approval the researcher met with the head of midwifery and clinical leads to discuss the research proposal and ask for approval to use the site for the research. The NHS Trust's research and development department was then approached and the research was discussed before application for ethical approval. The study protocol and all relevant documentation were submitted and accepted for approval by an NHS Research Ethics Committee (REC reference 15/LO/0068) (see Appendix 7 for study protocol). The study was conducted in compliance with the Research Governance Framework for Health and Social Care and Good Clinical Practice (GCP)(DOH 2005) (see Appendix 8 for ethics approval letter).

### **Informed Consent**

Study information leaflets were distributed in clinical areas including antenatal clinics, postnatal wards and community clinics (see Appendix 9, 10 and 11 for information leaflets). Informed consent was obtained for interviewing, recording, transcribing and possible publication of the anonymised findings. Participants were made aware that they could withdraw consent for specific aspects e.g. recording/transcribing. The safety of the researcher was taken into account following Social Research Ethical Guidelines (Social Research Association 2003). The NHS lone worker policy and other safety practices were followed (National Health Service, 2009).

### **Confidentiality**

The study complied with the Data Protection Act (Crown Copyright 1998) and the Department of Health Code of Practice for Confidentiality (DH, 2003). Manual files including tapes and paper documents were stored securely in a locked filing cabinet at King's College London in the Women's Health Department. No data included patient identifiable information. Audio recordings were transcribed using

pseudonyms or code names to protect the confidentiality of participants. Computer records were password-protected. Sources of data will be kept according to King's College London local policy on research data for 25 years, complying with the Congenital Disabilities (Civil Liability) Act (1976).

Interviewees were advised that if clinical safety concerns were raised in the interviews the researcher would immediately report concerns to a senior member of the clinical team and to her supervision team. This follows the Nursing and Midwifery Council (NMC) guidance which states "*as a nurse or midwife, you have a professional duty to put the interest of the people in your care first and to act to protect them if you consider them at risk*" (NMC, 2013).

Participants were advised that, if any malpractice was revealed during any interviews, the researcher may have broken confidentiality in order to safeguard patients.

### **Potential burden to participants**

The researcher has had previous experience of interviewing vulnerable women in addition to 20 years' clinical experience of caring for women and their families as a nurse and a midwife. This experience was valuable as during the interviews several women and their families discussed distressing events. When this occurred and if the participants become distressed they were offered the chance to terminate the interview and be referred for appropriate follow-up including being given contact details for additional support. This was offered to one woman, who chose to continue with the interview. Contacts of support groups including the Patient Advice and Liaison Services, APEC, Sands and BLISS (a charity for babies born premature or sick) were available if women wanted further information. For staff interviews again sensitivity was vital and referrals to staff support agencies were available if any of the healthcare clinicians interviewed became distressed during an interview when recalling a difficult clinical situation. This did not happen.

## 5.11 Reflexivity

As a practising clinical midwife and mother who experienced a complication in labour when giving birth, the researcher's reflexivity was essential throughout the research process to increase methodological rigour. Reflexivity was an important part of the research process for this study, from the formulation of the research question and methodology to the analysis, interpretation of data, and writing and dissemination of findings. There are several definitions of reflexivity, but for this research a methodological reflexivity approach was taken, whereby the researcher took account of her own relationship with the group she was interviewing i.e. she was conscious of her own prejudices and assumptions and attentive to sources of bias (Lynch, 2000).

In the field the researcher's role was clearly defined as a researcher and not as a midwife while interviewing. The researcher did not practice as a midwife in the organisation that she was researching in and her only role there was a researcher. This was a deliberate choice to avoid role confusion. In reality there may be times when it will difficult to be an 'outsider' as a clinical midwife. An outsider is where the researcher takes etic perspectives as an outsider to the community being studied (Geertz, 1973), as opposed to an insider who takes emic perspectives by being a member of the community being studied (Geertz, 1973). For example, possibly women may have chosen not to share concerns about their care as they may not have wanted to appear critical of the researcher's other professional identity (as a practicing midwife). However, during the interviews it was apparent that the women and their families had chosen to be interviewed because they wanted the opportunity to improve practice by sharing their stories.

As a midwife, the researcher's presence during healthcare worker's interviews may also have been perceived as threatening. For instance, at times the researcher felt that the healthcare workers held back on examples of poor practice within the organisation, perhaps due to loyalty to the place they worked. This occurred a few times and when this happened the researcher would try to reduce these concerns

before and during each interview by explaining the importance of confidentiality within research and that the research was not looking at individuals but at the whole, interacting organisational system. In addition at times it was difficult to remain passive during interviews. An example of this was when healthcare workers on the postnatal ward were describing the difficulties of responding in a timely way to help-seeking women when they were very busy. It was difficult not to acknowledge their difficulties, as the researcher, while working as a practicing midwife, particularly on postnatal wards, found delivering individualised timely care challenging due to the workload.

Another issue to consider is the potential for 'co-production' of the story during the interview, as the participant may have been influenced by the presence of the researcher and how the researcher interprets their stories (Riessman, 1993). The researcher may not always share the cultural (or subcultural) framework with the participants and may misinterpret on the basis of these assumptions (Holloway & Freshwater, 2007 p.14). To minimise this, the researcher checked out early findings with PPI representatives including meetings of the local Maternity Services Liaison Committee, National Childbirth Trust (NCT) and the local study site Pre-term Birth Studies Panel. This was really helpful as each group could recognise the credibility of the findings for the women and family interviews. One group felt that the way the findings were presented did not reflect more positive healthcare workers' contribution to women help-seeking such as provided by consultant continuity of care. The transcripts were reviewed following these insights. The aim was to continue patient-partnership involvement during dissemination of the final report. The preliminary findings were also reviewed by contemporaries and supervisors of the researcher, and presented at academic conferences to validate the findings and to minimise bias.

## **5.12 Summary**

This chapter has outlined the rationale for the narrative research methodology, epistemological and ontological underpinnings for the research and the research

design. Explanations were given for the sampling strategy and data analysis. Research governance concerns were discussed.

Chapter 6 below presents the analysis of data from the women and their families' interviews.

## **Chapter 6: Factors affecting help-seeking of women and families**

### **6.1 Introduction**

The purpose of this chapter was to describe the findings derived using thematic analysis of the interviews of the 23 women and five family members. This was answer the first two objectives, to identify the range of health concerns raised by women/partners/families, associated with signs and symptoms of pre-eclampsia or eclampsia during pregnancy, labour or the postnatal period which require urgent medical attention and secondly to identify the contextual factors i.e. information available, that influenced women/partners/families help seeking when raising concerns with health professionals.

### **6.2 Participant Characteristics**

The demographic breakdown of the 23 women and five family members was shown in Chapter 5, Table 6. In summary the family members interviewed included two mothers and three partners, see Table 7. Three of the interviews were dyad interviews at the request of the interviewees.

The women's ages ranged from 20 to 41. They were from a wide range of ethnicities and socioeconomic backgrounds. The majority of the women were primagravidas. A total of 10/23 women were high-risk at booking: high-risk conditions included twin pregnancies, chronic hypertension, diabetes, having had a kidney transplant and previous history of pre-eclampsia. Thirteen were low-risk at booking. The majority, 14, had a diagnosis between 37 and 39 weeks, with only three having a diagnosis before 33 weeks (see Table 6).

Women's ethnic backgrounds were diverse – White British, White European, Black British, Black African, Indian, Pakistani, and Asian other – and their educational

qualifications ranged from GCSE to post graduate level. All women spoke English, but some as their second language.

### **6.3 Brief overview: Themes and subthemes**

Five main themes emerged from the data: knowledge and understanding, signs and symptom perception, self-monitoring, trade-offs and organisational constraints. These and their subthemes are summarised in Table 10 and described in detail below.

Help-seeking was affected by an awareness of signs and symptoms pre-eclampsia; however, other social and organisational factors also influenced women's help-seeking, for example, how healthcare workers categorise women as 'low' or 'high' risk at their antenatal booking appointment. In addition, all the women and families interviewed referred to the significance of healthcare workers' interactions with them and the impact of organisational factors on their help-seeking. The themes and subthemes identified are shown in Table 10, below.

**Table 10 Factors affecting help-seeking from women's, their partners' and families' perspectives; Themes and sub-themes**

<b>Factors affecting help-seeking from women's, their partners' and families' perspectives</b>	
<b>Theme</b>	<b>Subtheme</b>
<b>Knowledge and understanding</b>	<ul style="list-style-type: none"> <li>• Level of knowledge/categorisation</li> <li>• Sources of knowledge</li> </ul>
<b>Signs and symptom perception</b>	<ul style="list-style-type: none"> <li>• Absence</li> <li>• Normalising</li> <li>• Range</li> </ul>
<b>Self-monitoring</b>	<ul style="list-style-type: none"> <li>• Taking control</li> <li>• Negotiating tool for own safety</li> </ul>
<b>Trade-offs</b>	<ul style="list-style-type: none"> <li>• Keeping pregnancy pathway normal</li> <li>• Prioritising family</li> <li>• Fitting in with the organisation</li> </ul>
<b>Organisational constraints</b>	<ul style="list-style-type: none"> <li>• Waiting for treatment</li> <li>• Not wanting to make a fuss</li> <li>• Consistency of advice</li> <li>• Medical dominance 'v' partnership</li> <li>• Postnatal care</li> </ul>

Whether and how the individual women's characteristics affected the findings can be seen in the discussion of themes and subthemes in the next section.

## **6.4 Theme 1: Knowledge and understanding**

Women and their families' knowledge and understanding of pre-eclampsia were shown to have an impact on help-seeking. Many of the participants interviewed did not have any prior knowledge or understanding of pre-eclampsia or its implications for their own or their babies' health. Many were also unaware of symptoms and signs of pre-eclampsia until after their initial diagnosis.

### **6.4.1 Level of knowledge**

The majority of low-risk women and their families had no understanding of pre-



eclampsia, the potential symptoms and signs associated with a deterioration in health, or how to seek help. This contrasted with the majority of the high-risk women, who considered they were offered too much information, although this subsequently facilitated their help-seeking as women recognised signs and symptoms and knew who to contact. The findings for both low-risk and high-risk women, as classed at their antenatal booking appointments, included women with a range of different characteristics, for example, age at completing full-time education, ethnicity or social background, and whether they were single or had a partner. There were a few cases who felt the level of information was correct and negative case analysis was used to further interpret these findings.

Findings from low-risk women are illustrated with quotes, below.

Study participant Woman 107 was primiparous, classed as low-risk at her antenatal booking appointment, and reported being unaware about pre-eclampsia, and had never heard the term, when she was diagnosed. At 37 weeks' gestation her pre-eclampsia was diagnosed during a routine antenatal appointment where she was found to have high blood pressure and proteinuria.

*“So, as I told you, I couldn't ... pronounce it, and I ask the doctor if he can write the name of the sickness because I never heard about this. So, it was shock for me because my pregnancy for this 37 weeks, it was perfect.” (W 107)*

This was similar to study participant Woman 114 who was also primiparous and had also been classed as low-risk at booking. She had called her midwife as she was experiencing diarrhoea and chest pain. She went to see her GP when she was 39+3 weeks' gestation, who sent her straight to hospital saying he thought she had pre-eclampsia, but did not give her any more information.

*“I had no idea what that was, never heard of it until then. So I was Googling it on my way there and the only way to clear it obviously is to deliver the baby, but luckily I was full term. When I got to xx hospital about 5 in the*

*evening they kept me and they induced me at 3 o'clock the following morning." (W 114)*

Among the partners interviewed, all described their lack of knowledge and understanding of pre-eclampsia. Below is a quote from a partner of a low-risk woman who was diagnosed with pre-eclampsia at a routine antenatal appointment. After his partner's sudden admission to hospital at 36 weeks' gestation, he rang friends and family as he knew nothing about pre-eclampsia at the point of diagnosis.

*"I had really had no idea about pre-eclampsia ... even with all my friends with babies, like no one had mentioned it. After she was diagnosed I saw things at work and I started to speak to my colleagues." (Partner of W112, Number allocated 113)*

These findings contrasted with women who were classed as high-risk at booking. A high-risk woman pregnant with twins (W109) was informed about pre-eclampsia at booking by healthcare workers, but also did her own research into the condition after the appointment, using the information offered by healthcare workers.

*"I knew about pre-eclampsia before anyway, from the very first appointment I had with the midwife ... no, not with the midwife, with the consultant. I was told that I was almost certainly going to get pre-eclampsia, so it was a kind of given. So I then read about it and researched it. I didn't have the actual consultant for the first appointment I had the registrar and I was told, I was almost certainly going to get it and what the signs and symptoms were." (W 109)*

Another woman, classed as high-risk at booking as she had pre-existing type 1 diabetes, felt risk factors were discussed so much it took the joy out of her pregnancy. She knew to bring herself to hospital and self-referred with significant symptoms and signs of pre-eclampsia at 33 weeks' gestation. Interestingly she delayed self-referral for 24 hours as she was not near her own hospital when her symptoms became apparent.

*“It was just ‘you need to come in because of your risk factors’. And also some junior members of staff that I saw, um, again they took the joy out of my pregnancy because they just talked about the risk factors so much that I just felt like, I just couldn’t be happy about being pregnant, because I kept worrying about still birth.” (W 116)*

A few of the high-risk women were happy with the level of information they received. For example, Woman 110, who had a previous kidney transplant and was informed of her risk of developing pre-eclampsia before she became pregnant, in a pre-pregnancy clinic, and throughout her pregnancy. She felt she was offered the correct level of information to identify risks and did not consider that she was ‘overloaded’ with information (W 110).

*“Obviously because I had a kidney transplant so I knew I was at a higher risk of having pre-eclampsia .....so it was all explained to me before because I went to the pre-pregnancy clinic, before I changed my tablets, and then before I actually started trying to get pregnant. So it was all explained, I knew any risks involved...” (W 110)*

An exceptional case, i.e. a high-risk woman who was not informed about pre-eclampsia, was also pregnant with twins but unaware of pre-eclampsia until her diagnosis at a routine antenatal appointment. She said that she was not told about pre-eclampsia until after she had been admitted. She was diagnosed at a routine appointment at 31 weeks, when her blood pressure was found to be high, and was subsequently admitted to hospital and remained as an in-patient until she gave birth.

*“No. I never knew nothing about pre-eclampsia. Um, it’s after like the next day when I stayed the twenty four hour – they were starting to tell me about it and stuff like that.....” (W 108)*

## **6.4.2 Sources of knowledge**

Once women had a diagnosis of pre-eclampsia, many sourced their own

information, with women describing the need to take responsibility for their care themselves and undertaking research about pre-eclampsia, regardless of whether they were high-risk or low-risk for the condition at antenatal booking. Women who were low-risk and who had not accessed any information about pre-eclampsia were often shocked at their diagnosis. They sourced information post-diagnosis from the internet, television, charities and friends and family. Some women had heard about pre-eclampsia from popular television programmes being screened at the time, such as the historical drama *Downton Abbey* and a reality television show *Keeping Up with the Kardashians*, where one of the characters/personalities involved had developed pre-eclampsia, but for most women and their families the internet provided the greatest source of information. Most women interviewed commented that a considerable level of responsibility was placed on them by health workers to do their own research. Many found the information they had sourced and read 'scary' and 'not helpful'.

Woman 106, a primagravida, high-risk at booking with an IVF twin pregnancy, perceived that a lot of responsibility was put on pregnant women and their families to do their own research due to the high workload of clinics. As she described:

*"Um, but, I think there is still quite an onus on mums to be do their own research to make sure that they are aware, and a little bit you are, kind of when you go to your checks, there is the ... 'we are an hour late, we are under pressure, we need to get you out the door as fast as possible' ... and it is kind of 'ok, we have done your blood tests, we have done your blood pressure, we have done urine and you are fine, off you go'. It's a little bit 'have you got any questions' as they are standing up..." (W 106)*

Knowledge from the internet and talking to friends and family were the most quoted sources of information women accessed, despite some being aware that this was not always accurate and had the potential to scare rather than reassure. One woman and her husband (W127 and P128) accessed support from the internet as they had received conflicting information during her in-patient admission. She was a primiparous woman who had been classed as low-risk at booking.

*"I don't know, I think it's worse in a way when they don't tell you ... like xx [partner name] mum said, when you don't get consistency, because then you do end up going on Google and convincing yourself that you are going to die, the child is going to die and, you know, that's the worst thing I think. When you don't have ... when you don't really know what's going on, you do resort to Google."*(W 127)

*"Mum's nightmares. The internet is a nightmare sometimes."* (P 128, partner of W 127)

One woman's Google search left her terrified she would die. She searched the internet just after diagnosis when she was on the antenatal ward. She was a multiparous woman and had been classed as high-risk at booking, with chronic hypertension.

*"When I checked it on the internet "pre-eclampsia is a silent killer" if you don't know you have it."* (W 121)

Similar findings were reported by partners, for example, Woman 112 described that her husband found 'death' on the internet when searching 'pre-eclampsia' so contacted friends and family for more balanced information as the following quote illustrates.

*"...and it was only speaking to husband's mum's friend that he started to calm down a bit. Because again he had got onto Google and typed it, and got death and this that and the other, yeah, I think for him some more information would have been a little better."* (W 112)

This was also the experience of Woman 123, who was having her first baby and had been classed as low-risk at booking, but was sent in to hospital by her GP at 38 weeks with severe pre-eclampsia.

*"My partner on the other hand was terrified – phoned his mum, and um, really thought I was going to die."* (W123)

These findings highlighted that not only were many of the women affected by a lack of knowledge of pre-eclampsia, but so were their partners, who often were at home alone and scared after the woman had been admitted. The lack of knowledge triggered them to do their own research, not only for their own reassurance, but also to support their partners who had had a diagnosis of pre-eclampsia.

Although the level of knowledge and understanding of pre-eclampsia facilitated or was a barrier to help-seeking, sign and symptom perception by the women and their families was also influential as an early warning to escalate concerns.

## **6.5 Theme 2: Sign and symptom perception**

Sign and symptom perception has been recognised as the first step to seeking help if an individual's health is at risk due to suffering a medical disorder or illness (Hay, 2008; Gijsbers Van Wijk and Kolk, 1997; Kolk et al., 2003), as discussed in Chapter 3.

Of note from this PhD study, is that some women did not experience any signs and symptoms of pre-eclampsia, or did not experience 'classic' signs and symptoms of pre-eclampsia, or feel able to distinguish these from perceived normal signs and symptoms of pregnancy. A wide range of other signs and symptoms were reported in addition to the 'classic five'. Family members sometimes promoted women's help-seeking by observing and commenting on their physical changes and persuading them to self-refer before the women themselves were aware. Conversely, in other cases when women asked family members about their concerns with their health or appearance, for example, swollen face or legs, these family members considered these signs as 'normal' in pregnancy rather than warranting referral to a healthcare worker.

### **6.5.1 Absence of signs and symptoms**

Women, their families and healthcare workers all identified that some women did

not develop 'text-book' symptoms and signs of pre-eclampsia. The first time they were made aware of a possible diagnosis of pre-eclampsia was at a routine antenatal appointment or by chance at another medical appointment e.g. a routine flu injection appointment at the GP.

One interviewee, Woman 101, was a primigravida who had been classed as low risk at antenatal booking. She reported she had been healthy and well up to a routine appointment at 37 weeks' gestation where she was found to have very high blood pressure and protein in her urine. On receiving a diagnosis of pre-eclampsia at this appointment she was shocked and found it hard to believe:

*"I didn't suffer any of the little symptoms..... I felt well.....I wasn't fat or big or how ladies look with pre-eclampsia, keeping water, nothing like this. I didn't have headache, I didn't feel like the ... how do you say, um ... yeah, I didn't feel anything, anything". (W 101)*

Some women who were at high risk of developing pre-eclampsia during their pregnancy at booking also reported they had had no signs and symptoms. The woman quoted below (W108), who was high risk with a twin pregnancy, also spoke of her shock to have a diagnosis of pre-eclampsia at 30 weeks' gestation following a routine antenatal appointment where she was diagnosed with high blood pressure and proteinuria. At interview it appeared she had had no physical signs and symptoms. As she explained:

*"And um, I was fine, I was normal all along, my pressure was fine and everything, and all I did was turn up for an antenatal clinic appointment and when I turned up for my antenatal my pressure was high, and they were like ... they kept checking it, checking it ... and they were like 'no, something ain't right', and then they sent me downstairs in the hospital to check it every fifteen minutes. Then they took a urine test, and then when they took the urine test they realised that there was protein in my urine as well as my pressure was high, and so they said they was going to keep me for twenty four hours, I stayed overnight." (W 108)*

An important finding is that women and health professionals recognised that not having physical signs and symptoms of pre-eclampsia was a common phenomenon which could clearly have an impact on a woman's decision whether, and when, to seek help. All the interviews were in the postnatal period and women were making sense of their experience retrospectively, so this may have affected the findings.

### **6.5.2 Normalising of signs and symptoms**

Some women, in contrast to those discussed above, described significant physical signs and symptoms, for example, severe headaches, epigastric pain and swelling of their hands and feet, but they or their family believed them to be 'normal' in pregnancy and did not seek immediate help from a health professional. Women gave numerous explanations for this delay: a lack of knowledge, believing the symptoms to be normal in pregnancy, or attributing the symptoms to other illness such as diarrhoea and vomiting. Others gave social reasons which will be discussed in the section on trade-offs.

The following quote illustrates how Woman 123, a primigravida and low risk at booking, and her mother both normalised significant signs and symptoms of pre-eclampsia. At 38 weeks' gestation she had significant swelling of her ankles and hands, headaches and visual disturbance which was also noticed by her own mother, but they both felt it was normal for pregnancy and did not seek help. A few days later she was diagnosed as having severe pre-eclampsia at a routine GP appointment when she went for a flu injection. She was delivered by emergency caesarean section the following day.

*"I didn't know I had it till I was 38 weeks - I had to go in for a vaccination at the GP and, um, a week before that I got to a stage ... my urine got to ... it was fine, and the following week when I went there they tested me and found protein in my urine ... and my swelling on my feet, I thought it was normal for pregnancy, but it was a bit too much that day when I went for the injection, and they checked my blood pressure as well and it was more than*



*high so they wrote me a letter to take to the, um, the hospital, the day unit ... 24 hour unit, or whatever, I don't know what it's called."*

*Interviewer: "Did you have any headaches or anything?"*

*"Blurry vision and the headaches ... it wasn't anything serious, it was just the blurry vision and the swelling, it got pretty pretty bad." (W 123)*

During her interview another women (W117) who was a primagravida and low risk at booking, normalised her signs and symptoms (possibly because she did not know what to look out for) as she did not think they were significant: She had a severe headache, was swollen and had visual disturbance to the extent she couldn't see properly. It was her aunt who probably saved her life by sending her into hospital because she noticed her niece was so swollen and symptomatic.

*"Well I didn't know I had pre-eclampsia because I wasn't getting any signs. It was like the last minute of my pregnancy and that's when my auntie told me to go to hospital to get a check up on what was going on because I was swollen, my foot was swollen. So when I came in that's when they did a blood test and I had four protein in my urine. That is what happened. I was having headache on that morning when I went to the hospital because I was seeing bright flashing lights, I couldn't see properly..." (W 117)*

Another woman (W111), who had intense shoulder pain as well as epigastric pain, was a primagravida and low risk at booking and was shocked at a routine 34 week appointment to be given a diagnosis of pre-eclampsia because of high blood pressure and proteinuria. During the interview with her, it was apparent not only she had epigastric pain and was unaware this was a sign or symptom of pre-eclampsia, but she had also experienced shoulder pain. This is a recognised sign and symptom of HELLP (Haemolysis, Elevated Liver enzymes, and Low Platelet count) syndrome (Pre-eclampsia Foundation, 2016). She attributed the shoulder pain to sitting at her desk.

*“Yeah, um, because it was quite uncomfortable. And one thing that I didn’t realise which was a symptom was HELPP Syndrome which was what I ended up having in the end, was the pain in my shoulder, and I thought it was just because of the way I was sitting at my desk. I had a desk assessment and it was fine when it came back but I didn’t really think anything of it.” (W 111)*

On several occasions, it was the women’s family who noticed signs and symptoms of pre-eclampsia, but at other times families normalised quite significant signs and symptoms and did not encourage the women to seek further medical assessment. In the case below Woman 119, a low-risk primagravida knew she was unwell, but her husband did not believe her and she was unable to contact anyone from the hospital.

*“...was basically reaching out to anyone, family/friends, who would then reach out to a family or friend, you know ... you know like, that was very kind of them because I didn’t ask them to but they felt they should, but I felt like ‘why is no one listening to me?’ I felt like a crazy person at one point. Just like this crazy pregnant woman who is just overreacting and I gave my husband hell for it. He knows now ... he knows that it was very irresponsible having never been pregnant ... he needs to listen, that I don’t make things up.” (W 119)*

However, some women normalised their symptoms, even when they and their friends who were medically qualified noticed they were symptomatic. Woman 115 was a multip who had experienced severe pre-eclampsia in a previous pregnancy. In the quote below she reports how she and her midwife friends normalised her signs and symptoms, even after using a urine stick which showed she had protein in her urine.

*“I remember my friends coming round, one of them was a midwife, and a lot of them are nurses, and they are like ‘are you alright xxx, you look really puffy’, and I remember saying ‘oh, you don’t think I’ve got pre-eclampsia do*

*you?’ Because a couple of them were midwives and so we obviously were talking about it. I was saying ‘I feel a bit puffy and my ankles are swollen, and I had a bit of a headache last night’ and, um, and then my friend was like ‘oh, I will bring round a urine stick and see if you have got protein in your urine’. She brought round one of the sticks and then we were all like ... we didn’t have the thing to measure it against and we were trying to remember what it normally looked like, and then neither of us could remember what it normally looked like and we were like ‘oh I’m sure it’s fine, I’m just over worrying’. So we had this joke about it and I didn’t do anything about it because ... yeah, and we were like ‘oh it’s probably just normal pregnancy things’.” (W 115)*

The way signs and symptoms were interpreted by friends and family members varied. Sometimes friends and families prevented further deterioration in an individual’s health as they were concerned by the appearance of the woman and encouraged her to seek help, but other times they normalised the early warning signs and did not encourage help-seeking.

### **6.5.3 Range of signs and symptoms**

Analysis of the data highlighted the wide range of signs and symptoms experienced by women, which included and, in some cases, exceeded the classic five highlighted by the RCOG (2012). Extreme tiredness was described by many women in the week leading up to diagnosis, some women noticed they were small for their dates, some had reduced fetal movements, one felt an irregular heartbeat, another shoulder pain, and several described feeling sick and having diarrhoea and vomiting. One woman recorded blindness in one eye, and one described sleep apnoea and Bell’s palsy the day before her diagnosis.

General exhaustion and tiredness were noticed by many women before their diagnosis, often in the absence of other signs and symptoms. Woman 119, who was low-risk at booking, had experienced extreme tiredness and reduced fetal movements but attributed these symptoms to being at the end of her pregnancy.

This could also be themed under 'normalisation', however, what is significant here is the extreme tiredness described by many woman in the absence of other signs and symptoms.

Extreme exhaustion was also reported by Woman 108, who was classed as high-risk with twins at booking, who had a sudden diagnosis at a routine 31-week appointment. Due to feeling so exhausted, she nearly missed her appointment.

*"I didn't see any because I didn't know about it, and um, I felt fine. I didn't feel sick, nothing like that, I felt normal. The funny thing about it that day I wasn't in the mood to go anywhere, I wasn't even going to turn up to the appointment because I was so tired, and I was like 'I can't be bothered', and then I was like 'you know, let me go'. I even turned up late to the appointment. And that's when they told me so lucky thing I did go as well."*  
(W 108)

Onset of diarrhoea and vomiting were experienced by some women just before their diagnosis of pre-eclampsia, as Woman 15 described:

*"No. I'm just trying to remember, um, another thing that I had is that I had really bad gastritis both times. And you know how they say if you get pains ... I can't remember what side it is."* (W 115)

Data from the current study highlights the variability of signs and symptoms experienced and the complexities this brings with it in terms of enabling women to recognise what is 'normal' and what might be a significant early warning sign.

Other signs and symptoms women reported are described under other themes, such as shoulder pain under 'normalisation', and growth of the baby and fetal movements under 'self-monitoring', emphasising the complexity of factors affecting help-seeking, and in some cases, several factors influencing each other.

Given that identifying signs and symptoms of pre-eclampsia are complex it is not surprising that women were using different methods of self-monitoring to assess their own health and safety, and identify when they needed to seek an initial

contact with a healthcare worker. These included blood pressure monitoring, urinalysis and weight gain.

## **6.6 Theme 3: Self-monitoring**

Several women discussed that they felt responsibility for undertaking their own research regarding pre-eclampsia. Others took control monitoring their health by using medical tools and equipment to maintain safety, for example, monitoring their blood pressure, urine protein levels, fetal movements, growth of the baby and weight gain. It appears that these women were using their skills and knowledge and measurements when “appearing at services and asserting candidacy” as a form of negotiation tool (Dixon-Woods et al., 2005; Dixon-Woods et al., 2006).

### **6.6.1 Taking control**

Some women found taking responsibility for their own care as empowering and others felt it was not their role and trusted the healthcare workers to take responsibility for them.

For example, Woman 106 was high-risk with twins at booking, as described previously, and was well-informed about pre-eclampsia both from her own research and discussions at her antenatal appointments. She felt she was going to develop pre-eclampsia because of her risk factors, so chose to regularly check her own blood pressure and urine at home and this is what alerted her to seeking help. It also reassured her knowing she was keeping ‘an eye on things’ herself and gave her the confidence to speak up when a midwife dismissed the significance of her raised blood pressure. It led to her seeking further assessment at her GP surgery and then at the hospital when she failed to get the response from her GP surgery she felt was necessary. As she described:

*“Weirdly I did my blood pressure every single day and charted it just in case, and it kind of stayed quite steady. It was going up but everyone kept saying ‘there is nothing to be concerned about’, and I kept saying ‘are you sure?’*

*Because you know that's quite high for me' ... 'well your blood is having to work a lot harder' and not being medical I don't know if that's true." (W 106)*

*"And had I not started to have ... when I was fighting to get that doctors appointment, had I not been doing all of the other checks at home I think I would have panicked, but also I think it could have quite easily been missed, whereas it was my little back up plan, I wasn't going to rely on it on its own but it made me feel a lot calmer knowing that I didn't have to wait two weeks or if they said 'you can't see the nurse' I could keep an eye on things myself." (W 106)*

Similar sentiments were expressed by Woman 115 who had had severe pre-eclampsia in her first pregnancy and was a nurse herself. During her first pregnancy she had an eclamptic fit, and was very nervous about her second pregnancy. In her second pregnancy she monitored her own blood pressure and urine with advice and support from her consultant obstetrician. She found this gave her control, empowerment and stopped her worrying between appointments.

*"So if you just have that one appointment every few weeks you wouldn't be picking up something that was ... so I definitely think that really helped me the second time, just feeling empowered. And also things like, I don't know how easy this is, if you are on the ward and it's busy, allowing you to medicate yourself, if you take your blood pressure medication on time, um, check your own blood pressure. I think sometimes we take power off people when they go into hospital or when they ... you know, rather than getting people to do it themselves ..." (W 115)*

Apart from using self-monitoring to reduce anxiety between appointments and to take control and feel empowered, some women used it a negotiating tool for their own safety.

### **6.6.2 Negotiating tool for own safety**

Women also used their self-monitoring readings as a negotiating tool to self-

diagnose, gain access to care or, interestingly, to delay admission to hospital or to self-discharge. Often women who had a good knowledge of pre-eclampsia and were self-monitoring were successful in accessing care. This was often the women categorised as high-risk at booking, but there were exceptions.

One woman used a weight app called Glow which alerted her to the possibility of pre-eclampsia due to her sudden increase in weight. It was this that led her to seek help in the hospital. Although she was categorised as low risk at booking and a primigravida, she worked as a health researcher and used her experience to research disorders of pregnancy including pre-eclampsia.

*“Luckily I was measuring my weight a bit, and yeah, interestingly, a bit unusual but I sort of had an app that I used called Glow, and it sort of plots your weight and your blood pressure, heart rate and so on. So I could see that my weight was getting slightly more at a higher rate than it was before, and then what really worried me was I measured my weight on Tuesday and then measured it again on Saturday, and I gained something like 3 kilos in four days. And then I thought ‘ok’ this can’t be, I don’t know, the baby or me overeating, it must be something else. I did a bit of Googling and one of the things they suggested was it could be water retention and it could be a sign of pre-eclampsia.” (W 118)*

Another primiparous woman who was low-risk at booking felt unwell at 36 weeks’ gestation and had difficulty accessing her community midwife and GP despite feeling so unwell she was in bed. She used a blood pressure monitor to check her blood pressure and became more forceful about getting help with these readings. She described:

*“... by Saturday I was in bed, I had my in-laws over actually and I just couldn’t um, couldn’t um, I was just feeling really bad, then I was starting to feel bad so I asked my husband for my blood pressure monitor just to see. The readings were very variable.” (W 119)*

Self-monitoring evaluation findings were used to negotiate access to care by other

women who were interviewed. For example, Woman 106 used her knowledge and confidence to get seen first at the GP and then later at the hospital. Despite the nurse saying not to come back for two days, she knew to seek help elsewhere. She had been self-monitoring her own blood pressure and urine.

*“Two days before I was due to see the doctors anyway, um and it was one of the GP recommended appointments that actually my GP surgery doesn’t do. It must have been ... I was 34 weeks ... it must have been a 33/34 week appointment which appears in your notes and says you just do this one at your GP. And when I called my GP to book it and they said ‘oh no, we don’t do that’ and I said ‘well can I just do it anyway’. ‘No, not really’. So I wasn’t allowed to see a GP for that appointment but I managed to force their arms to let me see a nurse.” (W 106)*

Blood pressure ‘bartering’ was often used as a negotiating skill not only to gain access to treatment but also to self-discharge from the hospital in the post-natal period.

For example, Woman 125, a low-risk primiparous woman, did “a deal” with the doctor to get home from the postnatal ward. She was informed by her medical background. After her delivery, her blood pressure continued to escalate on the postnatal ward and she was keen to go home so promised to come back in again the next day to have it checked.

*“...And that Sunday I had to do a deal with the doctor because I wasn’t meant to go home (laughs), and I told them ‘please, I want to go home’ (laughs, a lot). I can monitor my blood pressure at home and they said ‘oh, it’s really high’, and the deal was I go home and then I come back the next day and get my blood pressure checked. I said ‘ok, that’s fine’ (laughs).” (W 125)*

Blood pressure monitoring was also used by other women in the postnatal period as they couldn’t get to the GP appointment or they couldn’t get an appointment.



*“I tried to book an appointment with the GP, I actually got an appointment really quickly but then that day he (her baby) was breastfeeding like crazy. There is no way I could have gone to see the GP. So, yeah, in the end I just had to do it myself because I was getting worried that my blood pressure would go too low and I wanted to get off drugs anyway. So yeah, I got told off by the midwife, the community midwife (laughs).” (W 118)*

Two women were aware that their pregnancy growth appeared small for dates and had noticed reduced fetal movements. They had tried to escalate concerns about this, but their midwife, doctor and ultrasound scan were unable to confirm this. At delivery, both women were found to have intrauterine growth restriction (IUGR) babies.

Woman 114 was a primiparous woman who was low-risk at booking, and the midwife did not refer her for a scan despite no increase in fetal growth being detected for several weeks:

*“Two days before that I had been to my midwife and she said everything was fine. But in my notes it’s got like I had three appointments with my midwife. The first one they measure your bump and it was 34cm, then I went back a week or two weeks later and it was still 34cm.”*

*Interviewer: “And this is when you were 39 weeks?”*

*“And then when I went back again it was 33cm.” (W 114)*

Another woman described how she and her midwife thought her baby was small in her index pregnancy. Despite several scans this was not diagnosed until the birth, when she delivered an IUGR baby having had severe pre-eclampsia and started fitting during her labour at 38 weeks.

In all the other themes no obvious social characteristics patterns were recognised; however, the majority of the women who used self-monitoring were educated to graduate level, and the majority were high-risk at booking or monitored their blood pressure after their diagnosis of pre-eclampsia in the post-natal period. They all

spoke English well. Only one had been supported to self-monitor by the medical team; the others had all self-initiated self-monitoring. This theme could be seen to overlap with the theme of trade-offs where other social or psychological factors delayed women help-seeking.

## **6.7 Theme 4: Trade-offs**

At times women made decisions to delay treatment, together with their families, even though they were advised to have a medical intervention for their baby's and their own safety. Many spoke up to try to keep their pregnancy pathway 'normal'. Sometimes this was linked to women's high expectations of a natural birth, other times important family events such as a wedding, a religious holiday or lack of child care impacted on women's decision-making. Geographical location was also a factor as some women preferred to delay seeking help until they were near to their own hospital rather than go to a different healthcare facility. In other circumstances, as explored above, women used negotiating skills such as 'blood pressure bartering' to try and delay an escalation of care.

### **6.7.1 Keeping pregnancy pathway normal**

Many women wanted to keep their pathway normal in some cases because of fear. Woman 111 had planned a hypnobirth, where women use hypnotherapy to ease their birth, and had no previous knowledge of pre-eclampsia before her sudden diagnosis of high blood pressure at a routine antenatal appointment at 34 weeks. She was admitted immediately and had a caesarean section birth soon after. She describes how scared she was:

*“Um, but the doctors were really nice because I didn't want to have a c-section, I wanted to have hypno/hydro birth, um, so I was a bit upset and I was scared about having a c-section because I hadn't had an operation before in my life so the idea of having an operation scared me.” (W 111)*

Some high-risk women also wanted to keep their pathways as normal as possible, including Woman 109, who was high-risk with twins and wanted a vaginal birth. When she tried to negotiate to keep her birth as normal as possible she was informed of the potential risk of kidney injury and considered the language used to describe her risk was unnecessary:

*“Um, so they ... I had another one, Dr xx ... I think it was Dr xx who said ‘why do you insist on a natural birth when you are at risk of acute kidney injury’. That was her opening line to me before she said hello. And I was like ‘I don’t like your tone’. I had no idea what acute kidney injury was”. (W 109)*

### **6.7.2 Prioritising family**

Interview findings showed that women’s help-seeking was influenced in many ways by their family commitments. These included meeting the needs of children and spouse, wanting to be in the home environment, and attending family events.

An example was Women 112, who had been shocked at her unexpected diagnosis of pre-eclampsia after a high blood pressure reading in the community. She was sent for further assessment at the antenatal day care unit and was diagnosed with pre-eclampsia. She tried to negotiate to go home with treatment, as she was due to get married. Here the impact of her own expectations of a normal pregnancy contrasted with the diagnosis of a serious medical condition and this may have impacted on her ability to speak up with confidence. Her partner persuaded her to stay in hospital as he was worried ‘she would die’.

*“So as far as I was concerned I would sit on a heart-rate monitor for the afternoon and then go home again, and it will just be a jolly off work. After an afternoon sitting around in kind of the day unit at the hospital I finally spoke to someone, wasn’t monitored, my blood results came back and I was told ‘go home, get your bag’ or rather ‘get your partner to get your bag because we are going to admit you and induce the labour because your close enough to term for it to be safe’, at which point I had a bit of a fit and*

*said 'no, is this not happening, I am supposed to get married on Friday, just give me some tablets and I will come back on Saturday.'* (W 112)

Another example was Woman 114, who was low-risk and a primagravida. She was clearly unwell at home, although she did not know about pre-eclampsia, and it is possible she delayed seeking help as it was Christmas and she had her family staying.

*"I had diarrhoea and a bit of sickness ... Christmas day I was alright, but you are preoccupied because I have got two nieces who were running riot. So I wasn't thinking about it, but as soon as I was in bed I would feel unwell. Like I felt a bit sick, had belly ache."* (W 114)

Child care responsibilities were also reported by Woman 115, a multiparous woman who had been classed as high-risk at antenatal booking due to her history of previous pre-eclampsia. During the postnatal period she had started to feel unwell with the onset of headaches. She reluctantly took herself to hospital at 36 weeks' gestation with her young children as she could not get child care.

*"I checked it at home and I was getting headaches, and I was getting like kind of ... I was a bit twitchy which they felt in the end was just sleep deprivation. Um, I had rung my GP initially and then they had said that they weren't happy, that I should go back to hospital, but it was a bit difficult because, um, we obviously had two children. We sent both of our grandparents home for Christmas and didn't have any help, and it was xx hospital which was quite a long distance in a taxi."* (W 115)

At times women put the needs of their partners before their own safety. For example, Woman 125's blood pressure did not stabilise on the postnatal ward. She persuaded the doctors to discharge her, as she was willing to return to the hospital to have her BP checked on the following day. The woman said that her partner asked her to say she felt well, even though she was unwell, just so they could go home. She agreed with this as she did not want to be in hospital alone.

*“Wanted to go home (laughs). I was tired, and because my fiancé was sleeping on the floor he didn’t like the chair, um, the recliner chair, he was sleeping in ... they came at night and said ‘you’re not allowed to sleep on the floor’, but that’s where he feels comfortable. I can’t be in hospital alone. So all this, I didn’t want it to carry on. I wanted to be in my own home.” (W 125).*

Despite experiencing severe symptoms, Woman 116 chose to delay going to hospital for 24 hours as she was on holiday and did not want to go to another hospital. She preferred to go back to the hospital where she felt safe, which was the hospital where she had been having her antenatal care. When she did go in the next day she had an emergency caesarean due to the severity of her condition:

*“So I had swollen ankles, um, my face looked a little bit swollen, my hands were swollen. By the end walking was really difficult. I couldn’t wear any of my shoes. I bought sort of crocs that were like two sizes too big, I was just in a lot of pain. I couldn’t really sleep, um, everything was just really uncomfortable. I, um, I was snoring a lot because I think everything was just so swollen in the end I felt like I sort of had sleep apnoea – I don’t know if I did. Um, but I just looked ... I didn’t look well, and actually, um, a day or two before I went into hospital, the final time when I was told I had severe pre-eclampsia, um, I developed Bell’s palsy as well. So I noticed that my face ... in the evening, I noticed when I was brushing my teeth that I couldn’t purse my lips properly.” (W 116)*

This theme highlights the social complexity of help-seeking, where even with severe signs and symptoms and knowledge of the serious outcomes of pre-eclampsia if it is untreated, women chose to delay seeking help, prioritising other social concerns such as family or care provision and in one case, so that they could get back to the hospital they felt safe in.

## **6.8 Theme 5: Organisational constraints**

Organisational constraints impacted on women and their families in many ways. Subthemes included waiting for treatment, not wanting to make a fuss, consistency of advice, medical dominance v partnership, and postnatal care.

### **6.8.1 Waiting for treatment**

Many women felt confused as they experienced a delay in commencement of treatment after being given a “shocking” and often unexpected diagnosis of pre-eclampsia. This was compounded by the realisation that they needed urgent treatment due to the serious risks of pre-eclampsia to their own and their baby’s health. Delays in treatment once women had gone to hospital were often due to heavy clinical workloads with no beds available on day care units or antenatal and labour wards. These delays influenced women and their family’s ability to speak up about deteriorating health in active and passive ways. Emotional factors such as fear enabled some women to help seek, while others considered that continuity of care and partnership with healthcare professionals helped. In contrast other women were more accepting of delays either because they felt too ill to help seek or because they felt safe due to monitoring they were receiving or they felt that they were given sufficient information.

Many women discussed a delay of an induction of labour (IOL) as the staff were waiting for a bed to be available on the labour ward. Although some women did speak up they accepted that nothing could be done to accelerate their care due to the high capacity workloads of the units.

Woman 101 was diagnosed with very high blood pressure at 39 weeks’ gestation at a routine appointment. After admission on the antenatal ward she had a three-day delay before her induction of labour, as there were no beds available on the labour ward. Although she felt the baby was safe as staff monitored the baby’s heartbeat, she did speak up as did her partner, as they were concerned about the safety of the baby. The midwives were advocating for her but appeared

constrained due to the busyness of the unit.

*"It was Monday, and they were supposed to induce me straight away because my blood pressure was really high and they were just a bit worried, but there was no beds so it was a bit stressful." (W 101)*

The woman appeared to accept the inevitability of the wait; however, her partner (102) was less accepting. He felt that women in normal labour were prioritised over his partner and their baby whose safety was at risk. This made him feel "down".

*"Ten, eleven hours just to be admitted for a bed. We had been ... in the meantime they had obviously tested the urine and all that. In a sense it was high for pre-eclampsia. So you would have thought they would give her a bed a lot earlier. I understand you have got women already coming in that is already in labour, they need the beds more urgently. In that sense they are not really ... I don't know. It's hard to say ... I think that just me coming from because she is my missus in that sense you, but women coming and giving birth, and they get, you know, the chance to be discharged within, you know, six hours after their birth. So really and truly there should be enough beds but there isn't. We had to wait around for eleven hours just to be admitted for a bed." (P 102, partner of W 101)*

He described waiting for a postnatal bed as "an endurance" and although there was no choice but to wait, he felt that staff were trying their best for them despite the busyness of the unit.

*"I think it was six hours she come back and she said she was looking for another bed for you to be put on a postnatal ward. We was waiting around again for four hours. In a hospital, you know, for some reason it seems to be the fact that we have to wait around. Again it is an endurance thing. We have got to go through with it, we have no choice. I had to be there for them. Four hours have gone past, still no signs of a bed." (P 102)*

Woman 110 took herself to a walk-in centre because she had severe headaches and was feeling unwell. She waited for eight hours to be assessed, but did not

speak up to the healthcare workers, as she felt too unwell. She did ring her family at home for advice, who advised her not to self-discharge. She described waiting to see different staff and perceived that she had been forgotten by staff until the evening shift started. She was admitted and delivered soon after with severe pre-eclampsia.

*"I think they forgot about me at one point actually because someone said 'oh your still here', and I was like 'yeah, I've been here eight hours', and then obviously they swap shifts don't they, and then I think the on-call doctor, the evening doctor, then come down and that's when the decision was made to keep me." (W 110)*

Another woman (W 112) and her partner reported being very shocked at her diagnosis as she had felt well up to that point and knew very little about pre-eclampsia. The junior doctor informed her that if she went home it would be "curtains for everybody".

*"I understand that the day unit at the hospital isn't the best place to sort have a calm relaxed one to one with someone because there are people coming and going all over the place and it is very busy, but the person we did speak to was very matter of fact and said 'go home and get your bag because if we don't get this baby out now then it could be curtains for everyone', and I think that wasn't really necessarily the best way of dealing with it, especially with somebody who didn't really know what we were dealing with." (W 112)*

As she was told it was an emergency she could not understand why she then had to wait for treatment. After waiting for further assessment and treatment, it was another two days before she could be induced. She described it as an organisational disaster and found the conflicting advice that she received in terms of her need for emergency help confusing and upsetting. She spoke up for herself as her midwife who had sent her in advised her to do and reminded staff to take and send her bloods.



*“...it is an organisational disaster. Um, I don't know basically. I did ask 'is anything happening? I was told it is a walk-in centre and some people come in with emergency conditions, and I was told 'oooh, I was told I was'.”*

*Interviewer: “So you were waiting to see staff and for test results or ...?”*

*“The midwife in the antenatal clinic said 'tell them it is suspect PET and your blood will be rushed off immediately'. I did tell somebody that when I arrived and they said 'take your notes and wait over there', and when I went back an hour later to say 'I think somebody is supposed to take my samples', they said 'oh yeah, we will send them off right now'. So I think just a bit busy, lack of communication ... ah, it's a hospital. (W 112).*

Woman 115 had similar frustrations waiting for a bed to be free on labour ward so she could be induced, and when she tried to help-seek she reported finding it difficult to engage with a midwife as they were so busy.

*“I used to ring my bell and often it was a healthcare assistant and she would be like 'the midwife is busy, she will come as quick as she can'. I think they were just really busy. And then ... it was frustrating because they wanted to induce me but they kept telling me there were no beds on the labour ward, and I kind of felt like as soon as they induced me everything would be fine, so it was frustrating having to wait, um, longer.....” (W 115)*

This contrasted with Woman 114 who was sent in by the GP having been unwell at home for a number of days. She was seen almost immediately and had an induction of labour that night. She felt she had a good response from the hospital.

*“I went straight to antenatal in the xx hospital, and um, they were actually really really good. And the whole time I was there maternity and antenatal were brilliant. Um, they just took me in, put the monitors on to check the baby's heart rate, done another urine sample and there was 4+ still, then took my bloods and I had to just sit there for a little while being monitored*

*and waited for a bed. Then I got moved to the labour ward, and then I got induced at 3 in the morning.” (W 114)*

Another woman, despite having to wait three days for a caesarean section, reported feeling relaxed about the wait as she felt she was given a lot of information from doctors, and staff were responsive. She was high-risk at booking and her own knowledge of pre-eclampsia may have helped.

*“Of course waiting, and we don’t like wait in general but, you know, always informed, um, always you know with ... I felt really well attended so, you know, yeah it wasn’t so stressful me being there, just stressful because of waiting, you know being in the hospital.” (W 120)*

Woman 127 described feeling confused and upset about her wait, but did not help-seeking at this point as she rationalised that there was a doctor’s strike and other emergencies which were taking priority.

*“I think there were a lot of emergencies and there was a doctor’s strike for two days, so I think ... she said there was an unusually high amount of emergency c-sections. So you sort of don’t want to complain because I didn’t feel like I was ill. Do you know what I mean, but then I was also confused because I didn’t understand why the doctor ... I think in my head I was like ‘if it’s that urgent why has he sent me in?’ He was very much like ‘right I am going to book you to be induced the next day, the next morning, Tuesday, so then when it wasn’t booked in and nothing happened, I sort of ... you kind of feel a bit frustrated because ‘well why have I, you know, was I really that ill.’” (W 127)*

Woman 118 had been a reluctant in-patient for three weeks when the doctors felt she needed inducing due to a decline in her medical situation. She did not feel ready and managed to negotiate a one-day delay in her induction. The staff appeared supportive of her, maybe because she was knowledgeable herself:

*“... they said ‘let’s induce you today’, and this was just the day when my mum was going back, she was flying the next morning, so I was saying goodbye to her, and I didn’t really ... it came a bit too sudden for me and I wasn’t quite ready for it. Um, so I asked the consultant it maybe I could get induced the following day. I reasoned with her that actually, you know, my elevated ALT levels are not that elevated yet ...” (W 118)*

### **6.8.2 Not wanting to make a fuss**

Another woman delayed help-seeking as she herself was a doctor and used her own knowledge and diagnosing skills to rationalise to herself that her symptoms were not urgent and could wait another hour until ward round.

*“I woke up with the double vision, and I just ... I thought maybe I’m just a bit tired but it wouldn’t go away, and then I obviously told them when they came on the ward round.” (W 126)*

Both informed and non-informed women and partners were concerned about making a fuss. For example, one woman (W 116) acknowledged that being informed and living close to the hospital made it easier to feel she could come in and get checked over, but also worried about healthcare workers’ perception of her being a difficult patient.

*“Um, and, but again when you are going in quite a lot you do feel like your this ... you know, the difficult patient that keeps coming in, and then you sort of don’t want to come in, you know, again and again, um so sometimes you are like ‘well hang on, am I now just overreacting to everything?’” (W 116)*

### **6.8.3 Consistency of advice**

A number of women received conflicting advice from healthcare staff which influenced their decision-making ability, including whether to self-discharge or not.

*“It don’t know, it seemed like the consistency of advice, like you said earlier, you have been given, or you could do so this, you know you’re a patient, it’s*

*your choice if you are there really or not, you can escape if you want to but ... yeah, it's hard to weigh up a decision for non-medical people.” (W 127)*

Woman 127 found the conflicting advice difficult. She had wanted a home birth and heard the doctors saying she needed to be in hospital whereas her midwife was saying it was ok to stay at home.

*“Yeah the midwife was, yeah, cos xxx [name of midwife] our midwife came to visit us on antenatal didn't she, and she was sort of like saying ... she had spoken to the midwives on antenatal as well and sort of said, you know, 'she really doesn't need to be here, she could be at home', but the consultants were saying 'no, she needs to stay in'.” (W 127)*

She described the difficulty of having to decide which health professional to believe and reported finding the perceived risks of making the wrong decision overpowering. She and her partner decided to believe the doctors over the midwives, but were concerned about disrespecting the midwives.

*“I felt like the midwives were kind of ... they want everything natural don't they, they are kind of ... I don't know ... I guess they are thinking about the technical side of it but I feel like the doctors sort of see something, and they are like 'no, you need to do it this way'. The midwives would kind of rather you be in your home environment. So it is tricky to know, you know, when someone says to you, you have to decide what to do, I don't know, in my head I probably listened to the doctors, but not being disrespectful to midwives. Because I don't have any medical knowledge you assume that if a doctor says stay in you have to stay in.” (W 127)*

Her partner felt it would be easier if they did not have a choice and were just told what to do. The conflict between medical dominance and partnership is discussed in the next section.

#### 6.8.4 Medical dominance v partnership

Some women and their families felt continuity and partnership with the health carer affected their ability to speak up. Others felt being treated by staff as an equal and staff's use of non-dramatic language was a significant enabler for the women's subsequent decision-making and assertive behaviour.

For example, Woman 118, a low-risk primigravida, was offered conflicting information but described 'clinging on' to the version she wanted:

*"When I did the 24 hour urine one of the nurses told me 'oh, well you are peeing a lot so it is probably not pre-eclampsia', and I hung onto that quite a lot because I really wanted to go home. And then the next day when I saw the consultant he was sort of saying 'well we are still waiting for the results of the 24 hour urine test so we are not quite sure what is happening, but if it is pre-eclampsia then you are going to have to stay in the hospital', and that was good to know, but at that point he said 'it may not be pre-eclampsia'. I was still feeling quite positive that it would not be but then the next day when the consultant came to see me, they basically said 'yes, it's pre-eclampsia, and well really I don't understand why you weren't told this on Sunday.'" (W 118)*

Woman 119, a low-risk primigravida, was very vocal about the impact of the conflicting advice she received:

*"I just wanted to get the hell out of there but ... it was just like ... like the shifts of midwives, one of them will tell you one thing and another will tell you another thing, and another will tell you another thing ... and you are just hearing all of these things, and you are like, you know, they are literally contradicting each other. Once, a midwife was contradicting herself. I was just like 'what is going on'." (W 119)*

Woman 122 spoke up about the mixed messages she got about her medication. The midwives dismissed her views as the computer said she had had the drugs, however, the women reported that she had not:

*“I got mixed messages about the drugs that I should have been taking for the blood pressure. My drugs were either not given, not given on time, or were given ... on occasion they were given on time. The computer records ... when I spoke to someone later about it I said ‘this is my concern’. They brought up the computer record and said ‘oh, according to the computer record you have had all your drugs and you have had them all on time’. I said ‘this is not the case’.” (W 122)*

Woman 122 also felt it would have been helpful to have access to her notes which would have enabled her to speak up about her medication.

### **6.8.5 Postnatal care**

Although similar findings emerged from interviews when women described their postnatal care there were also additional specific problems. Many women not only had to cope with their own ill-health but had their babies in a Special Care Baby Unit (SCBU). Many found that the ward was so busy they could get little sleep and just wanted to be back at home despite their blood pressure still being high. Women appeared more assertive in the postnatal period and used negotiation skills to self-discharge even if it meant their health was put at risk. These were women from a range of backgrounds including different ethnicities and educational qualifications. Back in the community many women experienced difficulties obtaining care. They reported lack of communication between staff, clerical errors and workloads as contributing factors. Many chose to stop their own blood pressure medication as they could not get GP appointments.

Woman 108 who also had twins felt that even when she tried to get help in the postnatal period by ringing the bell nobody came as it was too busy:

*“Ok, um, like they haven’t got staff. Like you would call the bell, no one comes to you, you have to wait for a good twenty minutes, thirty minutes, before someone comes. When they do come they leave you to literally everything. It’s after you have just had a caesarean with twins, it’s difficult, and obviously like my family they are busy with work you know.” (W 108)*

Woman 115 had two very different experiences of postnatal care on the ward. She describes the first as 'chaotic' with no-one to help whereas her second experience was enhanced by her husband's presence.

*"... there was nobody giving you any help or telling you what to do, or helping you to express ... and again people were forgetting to check my blood pressure, giving me my medication late, it just felt like everybody was really in chaos. There was a woman opposite me just sobbing, sobbing. We used to talk to each other in the middle of the night and she just said 'I've got to get out of this place'. Yeah, it was just horrible."* (W 115)

Woman 106 was an in-patient for two weeks because her blood pressure did not stabilise. She had twins who were both in SCBU. Once she was back in the community, despite asking repeatedly, she had difficulties getting a midwife or health visitor to see her. She reported being made to feel that she was time-wasting and that there were other women more vulnerable than herself, even though she had been severely unwell with pre-eclampsia and had had premature twins born at 34 weeks' gestation. She finally managed to persuade a midwife to visit at home:

*"She eventually kind of came out with the hump, quite demonstratively with the hump, and then had a bit of a go at me for sort of time wasting and they are busy enough, and they only really come out to very special cases where you have got a sort of lone 16 year old who doesn't really know what she is doing, hasn't got much support or anything."* (W 106)

Her husband felt that everyone was caring for the babies but nobody was looking after his wife.

Woman 114 was an inpatient for seven days with "dangerously" high blood pressure post-delivery, but despite this she described very poor postnatal follow-up. Her midwife reportedly only came once and even when she had chest pains she did not come to visit her. The woman had run out of her blood pressure medications but did not know to get a new prescription from the GP.

*“I was supposed to ... when I got discharged, so I was supposed to have been told to go to my GP every two weeks to have ... but I didn’t. I didn’t know about that. When my blood pressure tablets run out that I got discharged with I was supposed to go back and see if I needed more but I didn’t know about that. I didn’t get told about that. Um, my midwife was supposed to come every day and check my blood pressure – she came once and then discharged me.” (W 114)*

This summary of the above findings highlighted the complexity of help-seeking for women and their families with pre-eclampsia.

## **6.9 Application of findings to Candidacy Theory**

The individual factors of help-seeking are applied to Candidacy Theory (see Chapter 3) to broaden understandings of the help-seeking trajectories of women with signs and symptoms of pre-eclampsia, and the influence of the service organisation, the NHS.

The table below highlights the application of the candidacy theory in relation to help-seeking and response to pre-eclampsia.



<b>Table 11 Stages of candidacy, facilitators and barriers to help-seeking and response</b>		
<b>Stages of Candidacy</b>	<b>Facilitators to help-seeking and response</b>	<b>Barriers to help seeking</b>
Identification of candidacy	<ul style="list-style-type: none"> <li>• Knowledge of signs and symptoms gained from HCW, friends and family or internet</li> <li>• Previous experience of pre-eclampsia or knowing a family or friend who had had it</li> <li>• Additional safety concern for unborn baby</li> <li>• Use of self-monitoring</li> </ul>	<ul style="list-style-type: none"> <li>• Categorisation at booking leading to knowledge given to some high risk women, not low risk women</li> <li>• Normalisation of signs and symptoms</li> </ul>
Navigation of the services	<ul style="list-style-type: none"> <li>• Knowledge of services provision. Pregnancy pathways complicated. Different services in community and hospital. Often multi-disciplinary teams</li> <li>• Categorisation</li> <li>• Bartering with promise to self-monitor at home</li> </ul>	<ul style="list-style-type: none"> <li>• Not all women knew about walk in services and some could not access midwives by phone or obtain GP appointments</li> <li>• Other family commitments prioritised over own care</li> <li>• Need for women to follow “normal” pathway rather than medical route</li> <li>• Categorisation</li> <li>• Normalisation</li> </ul>

**Table 11: Stages of candidacy, facilitators and barriers to help-seeking and response (*continued*)**

Permeability of the services	<ul style="list-style-type: none"> <li>• Routine regular antenatal appointments often identified women with pre-eclampsia before women did</li> <li>• Walk in services useful for access, but long delays sometimes lead to women speaking up</li> <li>• Language used by health care staff sometimes scared women</li> <li>• Categorisation</li> </ul>	<ul style="list-style-type: none"> <li>• The gap between routine appointments sometimes too long. Women having signs and symptoms in-between appointments</li> <li>• Sometimes women passive accepting delays due busyness of units or staffing shortages</li> <li>• Community postnatal GP access often limited</li> </ul>
Appearing at services and asserting candidacy	<ul style="list-style-type: none"> <li>• Women either used their knowledge of signs and symptoms or used readings from self-monitoring BP</li> </ul>	<ul style="list-style-type: none"> <li>• Sometimes signs and symptoms and self-monitoring treated as “normal for pregnancy</li> <li>• Sometimes clinical need or clinical availability affected candidacy especially when beds full on labour ward delayed treatment</li> <li>• Transfer from postnatal wards to community often poor communication between services</li> </ul>
Adjudications by professionals	<ul style="list-style-type: none"> <li>• Women valued being treated as humans when discussing care pathways</li> <li>• Women valued consistency of carer including consultant care</li> <li>• Categorisation of women</li> <li>• Bartering with promise to self-monitor</li> <li>• Speaking up for safety when regular checks such as BP or medication late</li> </ul>	<ul style="list-style-type: none"> <li>• Sometimes signs and symptoms or self-monitoring normalised by HCW</li> <li>• Sometimes conflicting advice from different medical teams confused women</li> <li>• Perceived threatening language sometimes used to persuade women to accept medical treatment</li> <li>• Difficulties of comorbidities affecting diagnosis and care pathways</li> <li>• Health care workers trying to manage workload by re-monitoring if high blood pressure result, possibly at risk of patient safety</li> <li>• Delaying transfer or escalation to keep organisational targets intact and workloads down, possibly at risk of patient safety</li> </ul>

<b>Table 11: Stages of candidacy, facilitators and barriers to help-seeking and response (continued)</b>		
Offers of/resistance to services	<ul style="list-style-type: none"> <li>• Sometimes women wanted to keep their pregnancies normal i.e. homebirth or water birth and tried to delay treatment</li> <li>• Sometimes women did not believe diagnosis feeling over medicalised</li> <li>• Sometimes in the postnatal period women wanted to self-discharge to be at home with their families before their blood pressure had settled. Putting family needs before their own safety</li> </ul>	<ul style="list-style-type: none"> <li>• Language used by health care workers sometimes perceived as threatening affecting decision making</li> <li>• Delaying treatment using own medical knowledge of treatment pathway</li> <li>• Offering to self-monitor rather than be an inpatient</li> <li>• Postnatal wards very busy sometimes delays in treatment and monitoring affected women speaking up. Some were passive accepting delays others spoke up</li> <li>• Geographical distance from known hospital delaying access to care until back from holiday</li> <li>• Coming off blood pressure medication as difficult postnatal access to GP</li> </ul>
Operating conditions and local production of candidacy	<ul style="list-style-type: none"> <li>• All women at risk of pre-eclampsia not just high risk women</li> <li>• Not all women get sign and symptoms</li> <li>• Families sometimes supported but other times hindered help seeking</li> </ul>	<ul style="list-style-type: none"> <li>• Possible discordance between NICE guidelines re information sharing for high and risk women</li> <li>• Hospital targets affecting transfers</li> <li>• Hospital resources affecting transfer</li> <li>• Hierarchal imbalances when junior staff identified high risk clients with high blood pressure</li> </ul>

These will be discussed in more detail in Chapter 8.

## 6.10 Summary

This chapter has presented evidence that awareness of signs and symptoms of pre-eclampsia influenced women's help-seeking. However, other obstetric, social and organisational factors also influenced women's recognition and help-seeking, including how healthcare workers categorised women at their antenatal booking appointment as either 'low' or 'high' risk. All of the women and families interviewed

referred to the significance of healthcare workers' interactions with them and the impact of organisational factors on their help-seeking.

An important finding was that some women did not experience 'classic' signs and symptoms of pre-eclampsia or could not distinguish these from normal signs and symptoms of pregnancy, with a wide range of other signs and symptoms reported in addition to the 'classic five'. Family members sometimes promoted women's help-seeking by observing and commenting on their physical changes and persuading them to self-refer before women themselves were aware. Conversely, in other cases when women asked family members about their concerns with their health or appearance, for example, swollen face or legs, these family members considered these signs as 'normal' in pregnancy rather than warranting referral to a healthcare worker.

Even though some women had significant physical signs and symptoms at times they did not seek professional help due to the influence of other complex social and psychological factors at the time, including family events, child care, geographical distance from the hospital and wanting to keep their pregnancy pathway normal.

Some women used self-monitoring equipment at home to identify more medical signs and symptoms of pre-eclampsia, for example, blood pressure, proteinuria or weight gain and used these measures to elicit help. The majority of the women who used self-monitoring were educated to graduate level, and the majority were high-risk at booking or monitored their blood pressure after their diagnosis of pre-eclampsia in the postnatal period. They all spoke English well.

Once admitted to hospital, constraints such as busy units and clinical hierarchies among staff affected women speaking up. Poor postnatal care pathways affected women speaking up in the postnatal period. Chapter 7 presents the analysis of data from the healthcare workers and PPI representatives' perspectives.

# **Chapter 7: Factors affecting healthcare workers' responses**

## **7.1 Introduction**

Chapters 1 to 4 identified the dearth of research exploring the factors affecting healthcare workers' responses to women presenting with signs and symptoms of pre-eclampsia. The aims of this chapter are to answer the third objective of the study, namely, to identify organisational, professional and social factors that influenced health workers' ability to respond to the health concerns raised by women and their families. Participant characteristics of those who were interviewed are summarised below.

## **7.2 Participant characteristics**

To meet this objective, 17 healthcare workers were interviewed from the same NHS organisation where women received their maternity care. As described in Chapter 5 Research Design and Methodology (section 5.7), purposive heterogeneity sampling was used to select the healthcare workers (Teddle and Tashakkori, 2009). Recruited staff included, 11 midwives, four obstetricians and two maternity support workers; this was in line with the recruitment plan. See Table 9.

Midwives represented Bands 6, 7 and 8 and senior and junior obstetricians were selected, including those in managerial roles. Staff with different job roles were also selected i.e. healthcare workers from community, antenatal wards, labour ward, early assessment unit, high dependency unit, maternity help line and postnatal ward. Healthcare workers' characteristics were presented in Chapter 5, Table 9. The five charity representatives were interviewed from five advocacy organisations and user groups who represented women and families who had pre-eclampsia. These included: Action on Pre-eclampsia (APEC), Maternity Service Liaison Committees (MSLC), National Childbirth Trust (NCT), Birth Trauma

Association (BTA) and MAMA Academy. No specific demographics have been provided as it would compromise their anonymity. Identification numbers were allocated from C 1 to C 5.

## 7.3 Brief overview: Themes and subthemes

Five themes and several subthemes were identified using thematic analysis to code the interviews. The themes were: information sharing, signs and symptoms, responsibility and self-monitoring, clinical need versus clinical availability, and relationships versus continuity of care (see Table 12). These themes and their subthemes will be discussed in detail from section 7.4 onwards.

**Table 12 Theme and subthemes identified from healthcare worker and charity group interviews**

<b>Factors affecting healthcare workers' responses</b>	
<b>Theme</b>	<b>Subtheme</b>
<b>Information sharing</b>	<ul style="list-style-type: none"> <li>• Concern for overburdening and scaring women</li> <li>• Categorisation</li> </ul>
<b>Differentiating signs and symptoms</b>	<ul style="list-style-type: none"> <li>• Knowledge of signs and symptoms</li> <li>• Comorbidities and complexity of diagnosis of pre-eclampsia</li> <li>• Social factors</li> </ul>
<b>Responsibility and self-monitoring</b>	<ul style="list-style-type: none"> <li>• Roles and responsibilities</li> <li>• Negotiating a timely response</li> </ul>
<b>Clinical need versus clinical availability</b>	<ul style="list-style-type: none"> <li>• Managing flow</li> <li>• Communication of risk</li> <li>• Meeting the needs of the organisation</li> </ul>
<b>Care co-ordination</b>	<ul style="list-style-type: none"> <li>• Antenatal</li> <li>• Postnatal</li> </ul>

## 7.4 Theme 1: Information sharing

In Chapter 6, one of the main themes identified by women and their families was how their prior knowledge and awareness of pre-eclampsia had impacted on help-

seeking. Healthcare workers were interviewed about these findings (see Appendix 4 for interview schedule), and offered a variety of reasons in response to women's/families' findings, including concern about scaring and overburdening women with information on pre-eclampsia and other potential pregnancy disorders. Many described offering individualised information depending on what the interviewee felt the individual woman they were caring for would want. All the healthcare workers, from each profession, discussed time constraints in busy clinics, and a few doctors and midwives recognised the importance for some pregnant women of focusing on 'normality'. The importance of language and breaking questions down by midwives for women was highlighted as beneficial for information sharing by a few of the interviewees. Some midwives and doctors also recognised that there might be variation in the content of information offered to women classed as either high or low risk at their antenatal booking appointment.

### **7.3.1 Concern for overburdening and scaring women**

All the midwives, with the exception of one, reported being concerned about overburdening women with too much information about disorders in pregnancy, including pre-eclampsia, and increasing the unintended effects that this may lead to, such as anxiety.

A community junior midwife (S 08) acknowledged that midwives often did not offer women information as they were reluctant to scare women, but needed to weigh up women's individual characteristics and lacked the time in busy clinics to offer in-depth individualised information on pre-eclampsia and other potential disorders. This midwife, like other health professionals, used her discretion to decide what information to give i.e. offering individualised information to women depending on their individual needs.

*"I also think there is a bit that is like most women have normal pregnancies and if you went through everything that could possibly go wrong - so you would then be onto things like gestational diabetes, placenta problems, pre-eclampsia, then actually they would be quite scared about what potentially*

*might happen to them, and also I think there would be information overload as well. So, you know, some women will take that in their stride and just be like 'ok, then I need to watch out for all these things because it might mean this', but other people will become quite anxious about that kind of thing, and I think, you know, you can't always tell which ones are going to go which way. So that's probably why I wouldn't go into it in so much detail. I think it's not just pre-eclampsia, it then leads into why you are not telling about all the other things that can potentially happen as well."* (S 08)

Interestingly, all of the doctors interviewed were aware women may not be informed about pre-eclampsia. One senior doctor (S17) considered that around half of the women they came into contact with had no prior awareness of pre-eclampsia.

*"I think it's 50% of them probably don't know anything about it. Um, and even if they know something about it they ... it's something to do with your blood pressure and you have to look out for headache and swelling of your hands, and um ... but I don't think the majority of women know exactly what pre-eclampsia is and how it affects you and the baby."* (S 17)

Only one midwife - a senior midwife who was a specialist working with women with pre-eclampsia - felt that it was more important to fully inform women about the risks to their health and their baby regarding pre-eclampsia, and this was more important than them being frightened by the knowledge:

*"They do have to understand more than just symptoms, like the seriousness of pre-eclampsia, because if you don't them ... yes, it can be frightening, but who are you to decide that this information may be too scary for that woman. It's not up to you, it's not your baby, it's hers. So she needs the information to make that decision."* (S 06)

All five senior representatives of charity groups, whose perspectives represented service users on a national level, reflected similar findings that many women do not



understand what the condition pre-eclampsia is, are unfamiliar with its symptoms and signs, and are unaware when and how to seek help.

A senior representative from one charity reported that women generally do not understand about pre-eclampsia. She felt it was important for women to know what signs and symptoms to look out for and the seriousness of the condition:

*“No. No, I don’t think they do. Um, yeah, I don’t think they understand. They don’t really understand what preeclampsia means anyway, and to be honest they don’t need to know the full ins and outs of pre-eclampsia just that, you know, it can be a serious condition and these are the symptoms and you need to look out for it.” (C 1)*

Another representative from a different charity felt that some women did know, and that those women who attended antenatal classes with the organisation were taught about pre-eclampsia.

Both health professionals and representatives from the selected charities described the importance of information tailored to the needs of the individual woman, similar to the findings of the healthcare workers. A representative of a third charity described the difficulties navigating how much information to give individual women:

*“Um, I ... it’s very ... you always get very divided views on this. I mean some women want all the information, and they want to know everything, and there are other women who are very happy to leave it to the health care professionals to sort of sort it out. So, um, the problem is I think health care professionals can be sort of damned if they do and damned if they don’t, because although we do have this mantra of ‘we should know the women’ you can’t really have that kind of intimate knowledge of how somebody’s mind works and how they think.” (C 2)*

Her point of view is echoed by many of the midwives and doctors who also acknowledged that different women may have individual requirements for the

amount of information they want.

In summary, even though healthcare workers were aware that women may not all be informed about pre-eclampsia, they often used their discretion in offering tailored care to the individual and in not wanting to overburden women. Time constraints were also a contributing factor for not giving information to women.

### **7.3.2 Categorisation**

The analysis suggested that categorisation played a significant part in determining why some women are given more information than others by healthcare workers. Healthcare workers concurred with the finding that information needs regarding pre-eclampsia varied depending on whether women were categorised as high-risk or low-risk at booking, which none of the charity group representatives interviewed seemed to be aware of. Not wanting to scare women was another reason they gave for choosing how much information to share. Both midwives and obstetricians acknowledged that the care pathways women were placed on at their booking appointment, i.e. high-risk or low-risk, contributed to whether the care assigned was consultant-led or midwife-led. Women allocated consultant-led care received more information than woman with midwife-led care regarding pre-eclampsia.

A senior birth centre midwife (S 02) reported that women who were high-risk would have consistently had more information on pre-eclampsia from both consultants and midwives throughout their pregnancies, and this would impact on women's awareness of symptoms and signs of pre-eclampsia and help-seeking.

*"Yeah, I think high-risk women, you know, women who may have had more input with consultant care, um, possibly those ones that are slightly more at risk ... age, twin pregnancies ... possibly those women are slightly more in tune with symptoms and knowledge because of the midwife is informing her of the symptoms, but also possibly the consultant is also asking questions about symptoms of pre-eclampsia. So possibly those women then are more in tune and aware of what to look for." (S 02)*

The intended and unintended consequences of informing all women about the risks of pre-eclampsia were emphasised by an obstetric consultant (S 14) who discussed the benefits of offering high-risk women targeted information on the condition, but at the same time was concerned about scaring women at low risk:

*"I think all of those women should be given extra targeted information. I think that all women should be given some information, um, without scaring them, and that's quite a difficult balance. But yes I think that ... I think that we have overdone the non-scary bit so we ... do we tell all women having their first baby they have got a 7% chance of preeclampsia? I probably wouldn't."* (S 14)

Another obstetric consultant described what he/she felt were the consequences of not always informing women about the risks of pre-eclampsia. He/she spoke about a woman who had an eclamptic fit in the postnatal period at home, and who had not been identified as high-risk and had known nothing about pre-eclampsia. He/she felt that if the woman had been recognised as being high-risk and given aspirin and had also known what to look out for, she may not have fitted at home. He/she was concerned that healthcare workers needed to listen more to women's concerns, and described that the woman who had the fit was concerned that no-one had discussed with her that she was at risk. The obstetrician described an appointment he/she had with the woman who had had a postnatal fit, and reflected on what would have improved her care and possibly prevented the outcome of a fit in the community:

*"I was talking to her later she said 'why didn't anyone tell me I was at risk?' I thought that's a bit strange, and I looked through her notes to see if there was any suggestion we had told her she was at risk and she hadn't been put on Aspirin, which suggested to me that we hadn't told her that she was at risk of developing pre-eclampsia. So she was an absolutely perfect example of somebody we should have recognised she was at an increased risk, we should have given her the treatment because she was at increased risk, and what goes with giving somebody treatment is explaining why you*

*are doing so and what that means and what to look out for. So I think that we ... I'm sure that we should be much better at that, and then we need to be, um, really listening to them when they come in and tell us.” (S 14)*

Healthcare workers and charity group representatives acknowledged that women and their families may not be offered sufficient information about pre-eclampsia. The reasons they gave for difficulties of gauging how much information should be given included not wanting to scare or overburden women, not having sufficient time, and the importance of treating women as individuals. Some women were offered more information than other women depending on their risk group and individual characteristics. The adverse consequences of this imbalance of information sharing regarding risks of pre-eclampsia and early warning signs to look out for was apparent in the women and family findings in Chapter 6.

In the following section healthcare workers describe how they understood why women sometimes had difficulty differentiating signs and symptoms of pre-eclampsia from normal pregnancy symptoms, and also how difficult it can be to diagnose pre-eclampsia, especially with comorbidities.

## **7.5 Theme 2: Differentiating signs and symptoms**

All the healthcare workers perceived the difficulty that women and families may have differentiating between normal signs and symptoms of pregnancy and the ‘classic’ signs and symptoms of pre-eclampsia and those that needed escalating. Some felt difficulties could be attributed to a lack of information about symptoms and signs, but others felt it was due to the complexities of determining onset, and that signs and symptoms varied from woman to woman especially if they had underlying medical conditions.

### 7.5.1 Knowledge of signs and symptoms

Most of the healthcare workers reported examples of women presenting with pre-eclampsia who lacked awareness of the seriousness of their condition, and had misinterpreted their signs and symptoms for those that are commonplace in pregnancy.

A junior doctor (S 03) recalled a story of a young woman he/she looked after in A&E. Even though the woman had had severe signs and symptoms of pre-eclampsia she had delayed coming into hospital until she was very unwell and thought she had food poisoning. On admission she had many of the signs and symptoms of pre-eclampsia, including headaches, epigastric pain and generalised oedemas. She was immediately transferred for pre-eclampsia treatment to a high dependency unit. In this situation the woman was unaware of the seriousness of her condition, but the junior doctor realised the seriousness immediately, and responded rapidly to the situation. He/she was so concerned about her, he/she did not wait for a porter to transfer her care from A&E, but took her to the high dependency unit him/herself.

*“I think it was a 19 year old girl, first pregnancy, um, had been feeling ... well she came into A&E, um, quite late on the evening thinking that she had very bad food poisoning. For the last two days she had been vomiting, um, had a headache, just felt very unwell, um, and then in the second day she developed some sort of epigastric pain, but that was because she was vomiting. I was the SHO on call then, um, as soon as she came up I came out of a different room. The MSW said ‘this lady has got a blood pressure of this’ so I just dropped everything and went to see her straightaway. She had, yeah, every single symptom, sign and symptom going and looked as though she was about to fit. So we got her cannulated, bloods, explained the whole sort of thing to her and I sort of highlighted that ‘actually I am really glad that you came into A&E thinking that you had got food poisoning, because if you hadn’t of don’t that then you probably would have ...’ I explained to her that she probably would have had a fit at home.” (S 03)*

## 7.5.2 Comorbidities and complexity of diagnosis of pre-eclampsia

Apart from awareness that not all women and their families knew about the early warning signs of pre-eclampsia, healthcare workers highlighted the complexity of comorbidities masking signs and symptoms. A senior obstetric consultant acknowledged that in his/her opinion there will always be misdiagnoses due to difficulties in differentiating some symptoms and signs from normal pregnancy changes to something more serious, and that this may be more difficult for women with pregnancies with underlying or additional medical complications such as epilepsy or renal disease, or women with chronic hypertension who may not be aware when symptoms are escalating due to pre-eclampsia rather than their medical condition. A woman with epilepsy who fitted and was referred to the neurology team to be seen in three months, did not have pre-eclampsia investigations:

*“...when I was a very junior doctor and somebody presented at 30 weeks’ pregnant with a fit to A&E.....and was referred to the neurologist and was given a new patient appointment in three months’ time. Possibly not the right management of a first fit in pregnancy, whether epileptic or preeclampsia, it’s not the right management and never was and, um, so I think that we have moved on from those days but I am not entirely convinced.” (S 14)*

Another phenomenon, not necessarily linked to comorbidities, was the difficulty of diagnosing pre-eclampsia even with medical tests such as blood investigations. This was mentioned by several healthcare workers who cared for women with significant signs and symptoms leading to further assessments, but who were found to have normal blood pressure and proteinuria levels. A senior midwife (S 04) was caring for one such woman:

*“..The urine was negative, but when we did send it to the lab and within 24 hours it came back positive. So it could have been missed quite easily with*

*a normal blood pressure and no proteinuria, only because of the symptom of headache, but ...” (S 04)*

The difficulty of diagnosing pre-eclampsia from signs and symptoms was highlighted above and this may cause a delay in response to deteriorating health. At times the discrepancy where signs and symptoms were noted by women, but objective markers such as urine analysis and blood pressure were normal, made a diagnosis of pre-eclampsia more complex and hard to navigate from the healthcare workers' perspective.

### **7.5.3 Social factors**

In Chapter 6, many of the women reported that they chose not to help seek as they did not want to make a fuss when healthcare workers were busy. This was corroborated by healthcare workers.

Complex social factors were recognised by a senior consultant who was aware that some women delay getting treatment as they don't want to bother the system or may have had an unpleasant experience previously. He/she acknowledged that giving women knowledge and empowering them to speak up may not solve the problem. The long-lasting effects of having their concerns dismissed could have an impact on future help-seeking.

*“... but it's also that problem for the women of they don't want to bother us, they are coming to see us in a couple of days' time, they have been up three times in the last month anyway and they always get sent away or somebody has been unsympathetic. So it's really really tough trying to get that balance so that we actually do pick up the women where we potentially could make a difference.” (S 14)*

Healthcare workers acknowledged that knowledge may affect women recognising their own signs and symptoms of pre-eclampsia, concurring with the women and family interviews. Another significant finding was the difficulty in diagnosing pre-eclampsia, as some signs and symptoms are similar to normal pregnancy signs

and symptoms. Comorbidities could impact on a medical diagnosis, and at times even with diagnostic tests pre-eclampsia could be difficult to diagnose. Healthcare workers acknowledged that social factors caused by interactions between women and healthcare workers could prevent women from seeking help in the future, for example, if healthcare workers were sympathetic to women the first time round the women may be more likely to help seek in the future.

## **7.6 Theme 3: Responsibility and self-monitoring**

In response to the women and family interviews where some women were using self-monitoring of blood pressure to aid help-seeking, healthcare workers were asked their views about this phenomena. Their responses ranged from being shocked that women were self-monitoring, to actively supporting those women who checked their own blood pressure at home. Many thought it could be useful, but that more research would be needed in this area. They worried about the quality and cost of home BP machines, and giving too much responsibility to the women.

### **7.6.1 Roles and responsibilities**

Many of the midwives were shocked when asked about women monitoring their own blood pressure or urine. Staff 13 was a senior midwife who did not agree with this as an option, which she referred to as not “blaming” women for doing it. She felt that some women may use self-monitoring as they have been exposed to negative stories from families or the media about continuity of care and therefore did not trust midwives to recognise if there was a problem. She also did not feel it was a pregnant woman’s role to be self-monitoring.

*“Wow, I’m quite shocked. Um, I suppose it’s similar to the listening to your baby’s heartbeat at home, um, I mean in some ways I don’t blame the women. I think probably people are anxious and there is a lot of ... you only have to read the Daily Mail website to get these horror stories of a midwife didn’t pick up this, perhaps the trust isn’t there particularly if you are seeing a different midwife every time.....I suspect there more trust issues or, you*



*know, a previous bad experience that's been passed down to them from their sister or mother, or something like that. I definitely don't think it's a good idea. It's not something I would promote. Um, so yeah, I would want to speak to the women about that."* (S 13)

Other healthcare workers felt that it could be useful if women were trained how to check their own blood pressure, had the skills to interpret the readings and were given a care pathway they could follow if there was an escalation of blood pressure. Others were concerned about the cost of the equipment and the quality of self-monitoring blood pressure machines available. Some were also concerned about the responsibility this would put on women to make decisions about their care pathways.

One of the junior midwives (S 05) felt that women could monitor their own blood pressure at home if they were properly trained to a level of expertise to ensure safe and meaningful monitoring and if they knew who to refer to:

*"Do you know what, I see pros and cons for it because one ... I guess it's not a bad thing if you are doing a blood pressure profile, but then it would mean educating a person - what does a blood profile mean, are you using the right cuff, what time of the day is it, does it mean that when you are using it at home it causes more anxiety if you have a one off reading because then it will lead to further high readings, you then have to explain that blood pressure alone does not mean anything, it has to be in context with other things, you know. So ... I don't know, there are pros and cons ..... and, you know, if you haven't got the knowledge to put that in context, of what use is that to you."* (S 05)

A senior obstetric consultant saw the value of women being able to monitor their blood pressure at home after the risks of preeclampsia had been discussed with them, but also felt that sometimes when women became really unwell their thinking may be affected and that may affect their judgement, such as happened to one woman the obstetric consultant had cared for.

*“She felt that she was ok and that she could monitor her blood pressure at home, and um, didn’t feel that she needed to be in hospital, um, even though we had discussed the risks and things, and actually once she delivered she realised that actually was probably quite unwell and that, you know, that affected the way she was thinking as well because ... yeah.” (S 16)*

### **7.6.2 Negotiating a timely response**

Healthcare workers recognised that women could use their blood pressure readings as a ‘lever’ to negotiate care. Some women were doing this using their own initiative, whereas in a few cases clinicians encouraged the women to say what their blood pressure was in order to get seen more quickly.

A senior midwife (S 09) described how she saw the value of women telling healthcare workers their blood pressure readings in order to get a more timely response in busy clinics:

*“..Um, when I am talking to women in the hypertension clinic, if they need to go into the day unit because of raised blood pressure, whether it’s preeclampsia or not, I always say to them tell them what your blood pressure is, because that’s what people listen to. That’s what people pay attention to. And that definitely speeds up the review of the women. Um, yeah.” (S 09)*

Although some healthcare workers interviewed felt that self-monitoring could be a useful tool for women negotiating access to healthcare, training was needed due to the complexity of the potential meaning of blood pressure readings and responsibility placed on women. Others were concerned about the quality and costs of the equipment.

## **7.7 Theme 4: Clinical need versus clinical availability**

Many of the women described long delays for treatment after an initial diagnosis of

pre-eclampsia (see Chapter 6). This left many women and their partners feeling frustrated and confused. Many 'spoke up' to accelerate their care pathway whereas others accepted the delay, as they felt well-monitored and informed and could see how busy the wards were. Healthcare workers were asked if they were aware of how these delays impacted on women's and their families' experiences of 'speaking up' and why these delays occurred. They were also asked how this affected their ability to respond. The subthemes described below summarise the data analysed.

### **7.7.1 Managing flow**

Most of the healthcare workers interviewed acknowledged that long waits occurred particularly in day units, antenatal wards and postnatal wards, often due to lack of beds and senior staff-mix shortages. They also acknowledged not only how this could impact on women help-seeking, but also on healthcare workers' ability to respond. The delays many women and their partners spoke up about often concerned induction of labour after a pre-eclampsia diagnosis.

Many healthcare workers felt that it would benefit women if they were informed of how 'triage systems' work and their place in the system. A junior maternity support worker (S 07) understood the importance of informing women how the triage system works and why other people may be seen before them. She felt sharing this with women would reduce their anxiety:

*"But it's just managing the flow and trying to keep everyone calm and reasonable and, you know, if you see someone that has been waiting there for like hours, even though they are not priority they need to be seen still – so trying to put them in a part where they are not going to keep getting pushed down to the bottom because then they will never get seen, because there is always going to be someone that is going to be prioritised over, if they come with like, you know, swollen toe and everyone else has got like really bad things." (S 07)*

Another senior midwife (S 13) acknowledged that often delays occurred for women

even after they had been told that they needed urgent care. She also felt that women needed to be informed why delays occurred:

*“... ladies that require induction of labour and we talk to women a lot saying ‘oh we need to induce you at this point because these are the risks to your baby, 1 2 3 4’ ..... and I completely understand it because we told them that there are all these risks to their babies and to their own health, and then suddenly say ‘oh sorry, we’re too busy.’” (S 13)*

Other healthcare workers described how the delays sometimes were in the interest of the woman and her baby’s safety i.e. explaining that their induction of labour had been delayed as there were not safe levels of midwives to deliver their baby. A senior midwife explained:

*“You tell them you have to induce them for a reason and then there is a delay, ok, so how are you going to manage that? Sometimes it is how you give the information to them and obviously we need to have beds to deliver them safely, and theatres, and sometimes it is not possible to start induction otherwise you will be in trouble. So, um, you obviously have to explain to them why we are waiting or delaying the induction because it is not safe to start the induction if there are no midwives or labour beds to deliver them.” (S 04)*

Staff 03, a junior doctor, acknowledged that women and their families were often given mixed messages, for example, the urgent need to be admitted for their own safety and then no beds being available for induction of labour. Often not being able to deliver care that was clinically needed due to the reality of clinical availability made him/her feel powerless:

*“Yes you do see things where it is a bit contradictory or a bit hypocritical, whichever way you want to put, it in terms of we are saying, yes it’s a big emergency, or it’s a serious condition, we need to keep you in hospital, this sort of thing, and yes there aren’t any beds on the antenatal ward, or we need to induce you because of pre-eclampsia - oh, but there isn’t any space*

*in the birth centre to induce you, therefore you need to hang around, which is ... then they are getting mixed messages ... or I would feel as if they are getting mixed messages if I was in their situation.” (S 02)*

*“You’re a bit powerless actually is the thing. I am not saying you need to induce someone you automatically get to induce them, it’s as if you have got clinical need on one side but then you have actually got clinical availability on the other side, and those two never seem to go hand in hand.” (S 02)*

The delays in treatment highlighted for some healthcare workers the importance of not only communication of triage and prioritising of care, but also communication of risk.

### **7.7.2 Communication of risk**

In the women’s interviews the emotional impact of delays and communication of risk often impacted on help-seeking. Healthcare workers were asked about this. Many of the healthcare workers interviewed had experienced expressions of frustration and anger from women who had been admitted to hospital, only to have treatment delayed. Some also felt that it was important how risk of pre-eclampsia was presented to women i.e. what would happen if they did not have treatment.

A senior consultant (S 14) acknowledged how high workloads in units led to delays in treatment. He/she also emphasised the importance of how busy units managed safety of care and how language used to communicate risk to woman could impact on the women’s own perception of risk. He/she also acknowledged that being managed in a safe way may not be the same as managed in a timely way.

*“So what the women are hearing is ‘you’ve got a dangerous condition we have got to deliver you’, and actually what we are saying is ‘you’ve got a potentially dangerous condition you need to be in hospital so that we can control that condition and deliver you sooner rather than later’, and it’s a subtle but very important difference. And yes it’s a busy unit but I don’t know that there is such a thing as a busy unit as staff level of business, and*

*therefore it's very difficult to always manage women in the timely way that they would like to be managed. They are managed in a safe way, but that's not the same as being done in a timely way.” (S 14)*

The same consultant also differentiated the difference between women who have late and early onset pre-eclampsia. He/she highlighted why there are different pathways of care depending on the timings and severity of presentations of pre-eclampsia:

*“At 32 weeks, unless they were very severe, we would be keeping them in hospital for weeks and managing their disease because it is better for baby to stay in. So the only reason we are getting on with it at 37 weeks is there is no advantage to the baby in waiting as opposed to because it is medically indicated to get on with it really really quickly. But they still have a disease that requires them to be in hospital where we can watch them. So, those differences are quite subtle...”(S 14)*

Some healthcare workers felt it was about giving women the correct information, for example, why women need to be an in-patient and be monitored, but not necessarily have their baby delivered. Gaining a woman's trust was important, as described by a senior consultant:

*“I guess it's to do with having trust isn't it and having to ... even if they are having a delay in getting their induction started that they still feel they are being cared for and being monitored appropriately, um, not just sat in a bed when they think 'I could be at home, because you are not actually doing anything different for me here', which I think is what you hear sometimes.” (S 16)*

The emotional impact of delays and communication of risk were acknowledged by healthcare workers on women, their families and themselves. Many of the healthcare staff interviewed had experienced expressions of frustration and anger from women who had been admitted to hospital, only to have treatment delayed either because of staffing issues, bed shortages or clinical reasons.

Communication of care pathways for pre-eclampsia was highlighted by both obstetricians and midwives as a way of reducing frustration and anger. A senior consultant (S 17) felt that communication was an important factor and that by grading pre-eclampsia women may understand why delays occur if they have “mild” pre-eclampsia:

*“Yes, and there is incredible frustration and anger sometimes because they say ‘well you admitted me because you thought that there was a problem and nothing has been done’, and I think we don’t give them a grading of how bad pre-eclampsia can get or how mild it be but we still want you to be in. So in certain hospitals you can have mild pre-eclampsia and go home.” (S 17)*

### **7.7.3 Meeting the needs of the organisation**

Healthcare workers gave reasons for delayed responses to managing women with pre-eclampsia, which included the need to protect colleagues from excessive workloads and the need to adhere to organisational policies and guidelines.

A senior midwife (S 1) described how sometimes women’s admissions to antenatal wards were delayed so that healthcare workers could comply with unit admission guidelines of completing procedures within allocated time slots. Concern for overloading colleagues with more work could also delay transfer of care.

*“... there is a set admission procedure that they have to do, um, and they are very good at it, but sometimes, even if the bed is ready, um, we have booked the bed ... so as soon as we think a woman needs to be admitted we will book the bed because it is easier to cancel it and wait than have to book it later if that makes sense. Um, but if the antenatal wards midwives often ask us out space out the women as there are things they have to do within the first thirty minutes of a woman arriving on the ward. So we try to do that and we explain to the women, keep them updated.” (S 1)*

Another example of delaying treatment was given by two midwives regarding the withholding of information about a woman's high blood pressure. This junior midwife reported being advised not to document an escalating blood pressure to keep a woman's care pathway normal, in order to prevent the additional work associated with escalating concerns, but she understood that this practice could be dangerous for the woman.

*"I just think it's really dangerous and it's the kind of thing that you are making a problem, that I felt like I was creating a clinical problem to keep a woman in in early labour because I was working in an environment that, you know, that was encouraging normality and the general message was 'if you find something like that don't come and tell us, keep it a bit quiet, retake it'. I'm not suggesting that they would completely ignore it forever if it went on and on, but the initial response was 'you're creating a problem, you shouldn't document that'." (S 11)*

Another more junior midwife (S 12) reflected that if a blood pressure reading was high often senior midwives encouraged her to use other machines to get a lower reading. She felt that at times she was encouraged to try to keep women "categorised" as low risk so that workloads would be reduced. She also felt that her own clinical skills were undermined as the organisation's needs were deemed more important than her own assessment of the situation. This may be a reasonable response from senior clinicians i.e. a double recheck of the blood pressure before escalation, however, it is interesting that these two junior midwives felt undermined if they did report high blood pressures and that they were creating more work.

*"Well I think I just felt consternation because I thought 'well actually I do know how to take a blood pressure', and I'm quite confident and I completely see that someone coming in with anxiety and pain may have a raised blood pressure and that may resolve, but it is still a raised pressure on a calibrated machine. And I don't think we should ignore that, and I find that happens on the postnatal ward as well. That the instinctive response of*



*a more senior midwife is often 'well go and take it with something else, go and find a different machine, you know, some of the machines are playing up today why don't take it with this instead'. It's like we want there not to be a blood pressure problem on top of everything else.'" (S 12)*

One of the charity group interviewees also reflected on having her blood pressure taken several times when she was pregnant. She perceived that different midwives displayed different skills and confidence levels when taking her blood pressure and how unreliable this felt to her. The number of times it had to be read led to her feeling stressed and believing that she was going to die alone in a side room:

*"...um, there was a real sort of variety of confidence levels with taking blood pressure. Some health care professionals would only want to use the old fashion pump, others were like 'no I don't do that' and they would go off and get the one that they were happy with, the electronic one. You know, fair enough, I appreciate difference, everyone likes to have their own ... more confident with certain things, but then you start to think 'yeah, but they're two different machines, done by different people'. Yeah, it didn't always feel particularly reliable." (C 5)*

*"...we are at this point where it has to be taken so often I don't get any respite 'oh my god, I might die'. I mean there was one particular dark point where I was genuinely convinced that was it, I was going to die in a side room because of my blood pressure and that no one would know I was there." (C 5)*

The same junior midwife highlighted the power dynamics within the healthcare setting and highlighted how this made her frightened of making the wrong decision when escalating her concerns to a more senior clinician, especially when it was busy. She felt that sometimes it was easier to delay to the next day's ward round for reviews. She believed that sometimes health care staff failed to escalate care in order to avoid generating more work with multiple demands on time:

*“Um, I think people are quite frightened to do something wrong ... let someone go home if their blood pressure is too high, or um, take that responsibility.... what the observations are doing, but if you’ve got someone that’s on regular blood pressure medication and they are quite well, then perhaps the delay in the discharge you might just think ‘oh well, tomorrow morning someone will come and review on the ward round and then they will be discharged, but actually they are sitting there quite happily now, so I will just leave everything as it is, I’m not gonna start getting reviews because then that’s gonna generate more work’. And I don’t mean that rudely. I just mean, um, you know perhaps there are lots of other things going on.” (S 13)*

Meeting the needs of the organisation affected how healthcare workers sometimes delayed care to women with pre-eclampsia, which included the need to protect colleagues from excessive workloads, power dynamics delaying escalation, and the need to adhere to organisational policies and guidelines.

## **7.8 Theme 5: Care coordination**

Women with pre-eclampsia often had multidisciplinary teams caring for them. They reported how this often lead to them receiving ‘mixed messages’ which affected their care from the initial diagnosis, through blood pressure monitoring at all stages, to admission, induction of labour, to postnatal care (see Chapter 6).

### **7.8.1 Antenatal period**

Care of women with complex medical conditions and comorbidities, and the mixed messages they sometime received, was described by many healthcare workers as frustrating.

A senior community midwife (S 10) acknowledged the frustration many healthcare workers experienced about the mixed messages being given to women, and felt that the different medical teams involved in care pathways often conflicted with each other regarding advice and this could affect women’s help-seeking and

delays in staff response.

*"I think it's frustrating for staff as well because we would like to be able to give a clearer answer to these women and, um, and you will get some teams thinking one thing and others changing those decisions that have been made. And I think ... it doesn't give a very clear message to women and I don't think they then know what to do with it." (S 10)*

Another example how miscommunication had occurred was reported by a junior midwife: a doctor had written a care plan about a woman with high blood pressure on a busy postnatal ward in the notes, but not told the woman or the midwife of his concerns. She felt this had occurred due to lack of time as it was very busy that day and the doctor had had a huge workload, and she did not see that he had written a care plan until five or six hours later.

*"...and I had been, um, talking to the doctor who is on the ward and asked her to go and review her. But the doctor had actually left the ward before coming back to me. She had actually reviewed the woman and she had documented a completely different care plan but she hadn't told me anything about it, so I don't know until about six in the evening when I came back to write up the notes myself. And what the doctor had documented was that she felt the woman was at really high risk of eclamptic fit but her blood results weren't good, she appeared to be deteriorating and the she was, you know, quite concerned and we should call her, you know, overnight if we were worried, or call the medical team. So that was like probably about five or six hour delay in me knowing what the plan of care was and that the doctor was that concerned about that particular patient, but the patient herself wasn't concerned." (S 12)*

She attributed this to lack of time, high levels of demand and the ward being busy, and describes the high workloads the obstetricians have on the post-natal wards:

*"...lack of time. They have a huge workload, um, there is no place to hide, so they are always out in a visible place and always being assailed by, you*

*know, patient after patient, midwife after midwife, and they are often being called away. So she might have told someone else who didn't tell me..." (S 12)*

A junior doctor also shared the difficulties in covering shifts generally. In one month there were 19 on calls that needed covering. He suggested a clear postnatal treatment plan to avoid mixed messages:

*"... I was having a chat with our coordinator today ... we are already two SHOs down and we had an email yesterday saying there were 19 on calls that need to be covered in the month of May [laughs]. So yeah, I think, yes ideally, and we would prefer that as well, but I think realistically that's not going to happen. Um, the only way to get round that is if you can't have the same doctor looking at someone's medications is to make all the doctors aware of a common postnatal treatment plan." (S 03)*

### **7.8.2 Postnatal period**

The difficulties of help-seeking and care coordination with concerns regarding pre-eclampsia in the postnatal period were discussed by all the women interviewed. Problems highlighted included lack of healthcare workers on busy postnatal wards to escalate concerns to and being discharged into the community with no follow-up if they had had hypertensive disorders in pregnancy. This was important as many women continued to have unstable blood pressure in the postnatal period. Many of the women had been seriously unwell with pre-eclampsia in pregnancy, and were discharged home on antihypertensive medication. Community midwives and GPs are responsible for the care of women following in-patient discharge and relevant issues were explored.

An important finding was that there were issues with coordination of care, particularly regarding ongoing management of hypertension. One of the community midwives (S 08) acknowledged the gap between women going home with the expectation that the GP would manage their hypertension, and GPs not knowing

what to do in terms of managing their medication.

*“I think there is a definite gap between, you know, people being sent home on one medication and the GPs not knowing that they should continue it or if, you know, a bit of ‘just have a six week check up with your GP and if your blood pressure is fine you can stop the medication’. That seems to be a kind of generic kind of rule that people give, where actually they should be going at probably two weeks to the GP for review and then continuing to have reviews after that until everything is stable again, so, yeah.” (S 08)*

This was also the view of one of the obstetricians (S 16), who referred to a communication ‘gap’ between primary and secondary care:

*“I guess it’s communication between secondary care and primary care, and the community midwives and, um, I don’t think that’s all terribly slick.” (S 16)*

A junior midwife (S 12) who worked on a postnatal ward also described postnatal care as fragmented, pathways as confusing and quality of GP care as varied:

*“Postnatal care it goes off the edge of a cliff basically, both in hospital and at home...I mean there could be all sorts of things obviously, and they don’t know, and they don’t know whether they should go to a GP or try and get back to hospital, or whether the midwife will know. The midwife may only come once and then send them to a clinic, and it’s often there the care becomes especially fragmented, sometimes conflicting, and they don’t know whether medication they have been told to take should be continued. So I think generally poor...” (S 12)*

Most healthcare workers, including obstetricians and midwives, reported difficulties with care coordination, including fragmented and sometimes conflicting care for women with pre-eclampsia. This affected the women and their ability to help seek as they often received mixed messages or did not know who to escalate their concerns to especially once discharged into the community in the postnatal period.

## 7.9 Summary

Healthcare workers had mixed views on how much information women and their families should be given about pre-eclampsia. Healthcare staff also recognised that information provision may differ in relation to high- and low-risk women. Reasons why healthcare workers did not inform all women about pre-eclampsia varied. They were often concerned about scaring and overburdening women with information about pre-eclampsia and other potential disorders. Many discussed using their discretion and giving individualised information depending on the woman's characteristics. They also talked about time constraints in busy clinics and the importance for some women of focusing on 'normality'. The importance of language and breaking questions down by midwives for women was highlighted as beneficial for information sharing.

Healthcare workers understood the difficulty that women and families may have differentiating between normal signs and symptoms of pre-eclampsia and those that need escalating. Some felt it could be attributed to a lack of knowledge, but others felt it was due to the complexities of signs and symptoms and that these varied from woman to woman, especially if they had underlying medical conditions.

Healthcare workers recognised that coordination of care was difficult to deliver for women with complex medical histories due to the number of teams involved, and they felt that women often received mixed messages about their care pathways.

Poor coordination of care and delays in treatment left staff feeling frustrated and powerless. Lack of time was given as a reason why miscommunication sometimes occurred; at other times it was lack of trust in machines and different techniques, for example, with blood pressure monitoring. Discontinuity of care for women with complex medical histories was described by many staff as a problem for themselves and for the women they were caring for.

## **Chapter 8: Discussion and conclusions**

This discussion chapter will interpret and explain the study results Chapters 6 and 7, and relate them to the research aims and objectives and the wider literature. The social theories of Candidacy Theory (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005) and Street-level Bureaucracy (Lipsky, 2010) will be used to enhance critical analytical understanding of help-seeking and factors affecting healthcare workers' responses.

The overall aim of this study was to improve care management and experience of women who had pre-eclampsia and their partners and families, by understanding factors that influence women seeking help with early warning signs and symptoms of pre-eclampsia, and healthcare workers' responses to women's concerns.

### **8.1 Overview of aims and objectives**

The four main objectives were:

- To identify the range of health concerns raised by women/partners/families, associated with signs and symptoms of pre-eclampsia or eclampsia during pregnancy, labour or the postnatal period which require urgent medical attention.
- To identify the contextual factors e.g. information available, that influenced women/partners/families help-seeking when raising concerns with health professionals.
- To identify organisational, professional and social factors that influenced health professionals' ability to respond to the health concerns raised by women/partners/families.
- To identify strategies e.g. information provided, in place to support women/partners/families to raise concerns, and how health professionals respond to them, including barriers and facilitators to their use.

As outlined in Chapter 5, a qualitative case study was chosen as an in-depth understanding was needed to meet the aims and objectives of the research question (Green and Thorogood, 2014). The study explored the experiences of

women, partners, families and healthcare professionals, using the principles of a narrative approach. Participants were interviewed with the interviews also having a semi-structured component (Arthur and Nazroo, 2007 p.111). Purposive heterogeneity sampling was used to select participants (Bourgeault et al., 2013).

Pre-eclampsia continues to be a leading cause of global maternal mortality with approximately 40,000 women dying each year (WHO, 2015). Since I started the PhD in 2013, outcomes for women with pre-eclampsia in the UK have begun to improve. The latest MBRRACE report (2017) found that the maternal death rate from pre-eclampsia and eclampsia continues to be low, but it is still a cause of death (Knight et al., 2017), with two women dying between 2012 and 2014 (Knight et al., 2014). However, this compares with 18 between 2006 and 2008 (CMACE, 2011). Reasons for the reduction in maternal deaths are unclear and cases over time cannot be compared, but could reflect implementation of new treatment pathways advocated by NICE (Shennan et al., 2017; NICE, 2016). These include prophylactic use of aspirin for higher-risk women, antihypertensive medication with lower thresholds, anticonvulsant therapies for women with pre-eclampsia, and planned delivery from 37 weeks' gestation for high-risk women (Shennan et al., 2017; NICE, 2016).

Despite the reduction of indirect maternal deaths, including those associated with pre-eclampsia/eclampsia (Knight et al., 2017), there remain known long-term effects of pre-eclampsia on subsequent maternal health, including an increased risk of cardiovascular disease later in life (Ahmed et al., 2014; Bellamy et al., 2007). Impacts on women's psychological health have also been reported. A prospective observational study conducted at one UK maternity unit found a clear relationship between women's experiences of severe maternal morbidity and post-traumatic stress (PTSD) symptoms at 6 to 8 weeks (Furuta et al., 2014). The findings of the current study contribute to understanding how care pathways could be improved to aid help-seeking and responses to it, and to reduce the emotional impact of pre-eclampsia.



It is unknown how many neonatal deaths are attributable to pre-eclampsia. However, although neonatal death rates from all causes have declined since 2008, from 3.2 per 1,000 live births to 2.7 per 1,000 live births in 2013 (Office for National Statistics, 2016), a recent perinatal surveillance report showed that the neonatal death rate remained fairly static between 2013 and 2015. This indicates that more work is required to prevent these deaths in the future. Morbidity risks to neonates include adverse perinatal outcomes, such as prematurity and intrauterine growth restriction (Steegers et al., 2010). A recent study in the USA evaluated the epidemiological and economic care burdens of pre-eclampsia using national data sets. They estimated that the cost of pre-eclampsia within the first 12 months of birth was \$1.15 billion for infants, with costs disproportionately attributed to births of low gestational age (Stevens et al., 2017). There is no comparable data available for the UK rates. The data from this study may provide greater understanding of help-seeking in pre-eclampsia and could contribute to improving neonatal outcomes for women who have pre-eclampsia.

Findings presented in Chapters 6 and 7 suggest that delay in help-seeking by women, when experiencing signs and symptoms of pre-eclampsia, and factors affecting staff response were influenced by a complex interaction of social, clinical, psychological and organisational structural factors (see sections 8.3 and 8.4).

## **8.2 Candidacy Theory**

Previously Candidacy Theory has provided a useful framework for understanding the complex negotiations service users use to engage in healthcare and explore the potential misalignment between the individual priorities and needs and the organisation (Hudson et al., 2016). As described in Chapter 4, other researchers have used the theory to analyse help-seeking trajectories mainly for vulnerable groups accessing services, for example, asylum-seekers, elderly, patients accessing care with illness and disability (Chase et al., 2017; Hunter et al., 2013; Dixon-Woods et al., 2006; Abbott et al., 2017; Mackenzie et al., 2013; Chinn and Abraham, 2016; Kovandzic et al., 2011; Koehn, 2009; Gideon, 2011; Coupland and

Maier, 2010; Bristow et al., 2011; Methley et al., 2016). Candidacy Theory was selected over the many theories and models on help-seeking, as what was lacking from many of these is the ability to incorporate the influence of an individual's perception of their healthcare worker's manner and competency on their experience of care (Methley et al., 2016). It was found to be a suitable framework to further explore women's help-seeking trajectories with pre-eclampsia, as their journeys often involved many stages and interactions with the health services and their 'candidacy' was seen to be affected by social and psychological processes.

To enhance Candidacy Theory, Symptom Perception Theory was used to understand how individuals recognise signs and symptoms of health deterioration to add further insight to the findings. As outlined in Chapter 1, pre-eclampsia onset can trigger early warning symptoms and signs of onset of severe pre-eclampsia, which may result in a woman's health deteriorating very quickly (RCOG, 2012a). Similar to Candidacy Theory, Symptom Perception Theory also recognises that many individual factors contribute to a person's help-seeking with signs and symptoms, including knowledge and normalisation (Moller-Leimkuhler, 2002; Gijssbers Van Wijk & Kolk, 1997; Leventhal et al., 1980), as described in Chapter 4. When applying Candidacy Theory to help-seeking for pre-eclampsia, several of the dimensions appeared to correlate; however, there were also disparities.

The findings in Chapter 6 showed that negotiation skills were used by women and families across the maternity pathway i.e. not only to access care, but also when they were in-patients, when these skills were used to escalate their care, to ensure they were safe, to de-medicalise care or to speed up the discharge process. Once discharged back into the community, negotiation continued to be a skill that women and their families needed in order to navigate access to care. Individual women's characteristics which were found to impact on candidacy included if women had had pre-eclampsia before, or whether they were classed as low- or high-risk at their pregnancy booking appointment. Women included in the study who achieved a higher education level also used self-monitoring tools such as blood pressure monitoring to assert their candidacy. Table 9, Chapter 6 included facilitators and

barriers which helped when seeking response for pre-eclampsia, using seven overlapping stages in the process of negotiating candidacy: identification, navigation, permeability of services, appearing at services and asserting candidacy, adjudications by professionals, offers of resistance and operating conditions (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005; Mackenzie et al., 2013). This table highlights what factors affected candidacy for women help-seeking with pre-eclampsia i.e. having knowledge and understanding of pre-eclampsia, signs and symptoms perception and using self-monitoring to assert candidacy. Similar to Mackenzie et al.'s (2013) findings, women with pre-eclampsia had multiple candidacies that acted or competed in conflicting ways, so at times women traded the needs of family commitments over their health, but they also had the inner conflict of wanting to keep the unborn baby safe in the antenatal period.

The women and family interviews presented in this thesis highlighted that candidacy was affected by knowledge and understanding of pre-eclampsia, signs and symptom perception, normalisation, self-monitoring, trade-offs and organisational constraints.

### **8.2.1 Women's knowledge**

It was apparent that women's knowledge and understanding about pre-eclampsia affected their identification of early warning signs and symptoms and subsequent help-seeking. This affected their candidacy as they knew what to look out for. Other researchers have similarly identified that women may not know about signs and symptoms of pre-eclampsia which subsequently impacts on their help-seeking (Gudu, 2017; Leeners et al., 2006; Sauvé et al., 2008; You et al., 2012; Brewer et al., 2015; Kidner, 2004; de Souza et al., 2007) and it was a significant finding in the narrative synthesis in Chapter 4 (Carter et al., 2017). As previously mentioned other help-seeking theories, including Symptom Perception Theory, have also identified that one of the first steps to seeking help is knowledge and the identification of the symptoms of the disorder or illness (Hay, 2008; Kolk, et al.

2003; Gijsbers Van Wijk and Kolk, 1997). Previous researchers using candidacy have highlighted how information about an illness affected identification of candidacy (Methley et al., 2016; Hudson et al., 2016). For example, in a qualitative study of parents and carers of South Asian (n=49) origin of children who suffered from asthma, showed that identification of candidacy and help-seeking was affected if they knew about asthma (Hudson et al., 2016). Interestingly, the parents and carers in this study reported that advice was often given by relatives and close friends (Hudson et al., 2016) or if they knew someone with asthma. These findings concurred with Leventhal et al.'s common sense model (CSM) which evolved from a study examining community responses to the 1957 flu pandemic which showed that participants who experienced symptoms or saw family members or a close friend fall ill were more likely to believe they were at risk and take action (Leventhal et al., 2016a). It has since been used to explore other clinical conditions including hypertension (Meyer et al., 1985) and post-partum depressive symptoms (Howell et al., 2006).

The findings in Chapter 6 concur with findings of Hudson et al. (2016) and Leventhal et al. (2016) i.e. knowing about an illness (pre-eclampsia in this PhD study) either from having it in the past or from healthcare workers, social media or friends and family can facilitate help-seeking. These findings are also reflected by application of Symptom Perception Theory whereby knowledge of the illness was external information, including social context (Moller-Leimkuhler, 2002; Gijsbers Van Wijk and Kolk, 1997)

### **8.2.2 Categorisation**

What this study adds to the body of literature is the role that risk categorisation played in provision of information and help-seeking for women with pre-eclampsia in the UK, and how this impacted on their candidacy. The impact of staff risk categorisation of patients on their subsequent help-seeking behaviour has not been identified in other help-seeking models (Leventhal et al., 1980; Kolk et al., 2003; Gijsbers Van Wijk & Kolk, 1997; Lee et al., 2012; Moller-Leimkuhler, 2002).

However, previous literature has also recognised and written about categorisation and the dominance of the biomedical model where the task of the healthcare workers, increasingly in the 19th and into the 20th centuries, was to 'translate' pieces of information into a definitive diagnosis that linked the disease to specific biological causes and outcomes, which did not include the importance of the patients' circumstances or lifestyle, let alone their beliefs or values (Bury, 2001; Skjervheim, 1959; Thesen, 2015). Thesen also recognised that clinicians cannot avoid categorising the patient's pattern of symptoms and signs in order to reach diagnosis and treatment (Thesen, 2005); however, by doing this the human side is forgotten.

Women interviewed who at booking were categorised as low-risk, said that they knew nothing about pre-eclampsia despite regular attendance at antenatal appointments and access to social media. For low-risk women this was pertinent as they felt that by being categorised as such, potential lifesaving information was withheld, taking away their ability to help seek without prior knowledge of pre-eclampsia. All the low-risk women were unhappy with the poor level of information they were offered antenatally and would have liked more information about pre-eclampsia. This included women of all ethnicities, educational level and social group. 'Categorisation' may also have impacted on their shocked reactions when they were given a diagnosis of pre-eclampsia as they were unprepared. For many low-risk women who had expected to have a normal birth and were planning a homebirth, use of hypnobirthing and water birth, a diagnosis of pre-eclampsia meant that their birth plans could no longer happen as their health had deteriorated. This could explain why so many found their diagnosis difficult to accept and wanted to go home or continue their plans for a 'normal birth'. Nearly all the low-risk women described being shocked at their initial diagnosis whereas the high-risk women were much more prepared and had often self-diagnosed themselves and used this knowledge to seek help.

These findings contrasted with women who were categorised as high-risk at booking; these were the women most likely to use self-monitoring such as taking their

own blood pressure at home and using these readings to further enhance their candidacy when help-seeking. As discussed in Chapter 4, this is similar to individuals becoming the 'expert patient' (DH, 2001a) where in creating expert patients, individuals are better able to take responsibility for self-management of their own long-term healthcare needs. Although 'self-management' was seen to influence candidacy, for some categorised as high-risk at booking (mainly women educated to degree level), only one woman reported the health-care worker supporting her to self-manage. The other women relied on their own research to self-monitor, perhaps teaching themselves to become 'experts'.

### **8.2.3. Self-monitoring**

Self-monitoring of blood pressure in general healthcare is not a new concept. A recent systematic review and thematic synthesis of patient and provider perspectives in 12 studies concluded that there are three overarching themes in worldwide qualitative literature which support findings of the current study, namely, that self-monitoring of blood pressure could improve autonomy and self-efficacy and change the traditional patient-clinician dynamic (Fletcher et al., 2016). None of the studies included in the review by Fletcher et al. (2016) were for pregnant women with pre-eclampsia, and nor did they identify if self-monitoring facilitated help-seeking. Nevertheless, it is encouraging to report similar findings. An earlier paper by Hodgkinson et al. (2014) which explored the use of blood pressure self-monitoring for pregnant women, concluded that self-monitoring of blood pressure was feasible and acceptable to pregnant women and felt it might make antenatal care more effective, but recommended further research to establish safety and efficacy as well as the impact on women and health professionals (Hodgkinson et al., 2014). This is supported by a retrospective study in Pennsylvania, USA, of 100 women, which investigated the relationships of psychological stress, preeclampsia/gestational hypertension symptoms, confidence in self-monitoring, well-being, and perceived social support with pre-eclampsia/gestational hypertension disease progression in outpatient women. Interestingly, the researcher compared the differences in these variables with those of women with

mild and severe preeclampsia/gestational hypertension attending outpatient appointments (Black, 2007). Although the researcher concluded that there was no difference between the high- or low-risk women and their confidence in self-monitoring, all included women were supported with self-monitoring and the study was not looking at how women used self-monitoring to help seek or assert candidacy (Black, 2007). What was interesting in this PhD research was that women (mainly self-initiated and self-taught) used their blood pressure readings and other self-monitoring initiatives such as their weight gain, urinalysis, fetal growth and fetal movements, to identify candidacy and to 'navigate' the services i.e. bartering to self-discharge from the postnatal wards if they promised to self-monitor their blood pressure at home.

In this PhD study, self-monitoring was used in several stages of Candidacy Theory to identify candidacy and to access care i.e. the levels of negotiating candidacy: identification, navigation, permeability of services, appearing at services and asserting candidacy, adjudications by professionals, offers of resistance and operating conditions. Interestingly, under 'offers of resistance women used self-monitoring to delay treatment or to self-discharge, choosing their own medical pathway over healthcare workers' advice. Often it was their concern for their babies' safety that ultimately persuaded them to comply with the medical pathway. This use of negotiation and bartering has not been discussed in other help-seeking models or theories in pregnancy. An unusual finding in this PhD study was how women sometimes used self-monitoring to delay rather than to escalate treatment. The healthcare worker's perceptions of candidacy and self-monitoring varied. Senior obstetricians at times supported women to do this, but all healthcare workers were concerned about the level of training women would need, and the costs and reliability of blood pressure machines. Fletcher et al.'s (2016) systematic review also found that some healthcare workers were uncomfortable with the reliability of self-monitoring blood pressure readings, but in the review patients and clinicians felt that self-monitoring was empowering for patients and assisted them in managing their blood pressure. None of the studies synthesised were of pregnant women.

Another finding of the current study was that categorisation affected when women and their families undertook internet searches of the condition. This was significant for the low-risk women who knew nothing about pre-eclampsia before their diagnosis and searched the internet for the first time after their initial diagnosis of pre-eclampsia. This left many women scared for their own and their baby's mortality. This impacted on their candidacy and experience of pre-eclampsia; for some, fear of their mortality as a result of reading about pre-eclampsia online was used by them or their family members to question why there were treatment delays in busy units. Family and friends also described using the internet for information about pre-eclampsia so that they could support the women. The use of the internet by women as a source of knowledge for pregnancy is not new (Sanders and Crozier, 2018; Lagan et al., 2010; Larsson, 2009), but what is new is the impact of internet searches on pre-eclampsia after a sudden diagnosis and the fear these searches caused.

Although the women who had been classed as high-risk at pregnancy booking appeared to have benefited from knowing much earlier about their risks of pre-eclampsia, many felt this knowledge had a negative impact on their pregnancy experiences. Most of these women felt they were offered too much information, and a few believed the stress of this triggered the development of pre-eclampsia, although there is no basis for this in the literature.

This reflects comments in a recent editorial included in the journal *Midwifery* regarding risk and childbirth, where the authors felt that *"the issue here is not that risks are discussed with women, but rather that such discussions are often unbalanced, focusing on unlikely but dramatic adverse outcomes without explaining the potential health gains for women and babies of careful and ongoing assessment, and considering options that are likely to incur fewer interventions overall."* (Coxon et al., 2016). In this PhD study there were some examples of women who considered that they had been offered the correct amount of information. For example, one woman who had a long-term high-risk medical history felt that she had the appropriate amount of information and she used this



knowledge to seek help when she became symptomatic again, perhaps reflecting on the importance of the 'expert patient'. There is little research available on the appropriate amount of information to give to women and their families about pre-eclampsia or how to tailor the information to the needs of the individual.

#### **8.2.4 Normalisation and risk perception**

Chapter 6 identified that a number of other factors apart from knowledge impacted on help-seeking i.e. symptom perception. At times even though women had significant signs and symptoms they did not seek help due to complex social and psychological factors; sometimes they would barter to delay treatment or to stay at home by offering to self-monitor. For example, symptom perception could be seen to relate to candidacy, where individuals may not identify themselves as candidates for care when they experience mild symptoms or are asymptomatic (Methley et al., 2016)

Many reasons could be postulated as to why woman may not seek help even with signs and symptoms of pre-eclampsia, including 'normalisation' which is usually discussed in terms of chronic illness. It is defined by Bury (2001) as having two kinds of processes: the first is where patients may try to 'normalise' their illness and keep their pre-illness lifestyle and identity intact; and the second refers to the disguising or minimisation of symptoms in behaviour and in accounting processes (Bury 2001). It was also identified as a factor that affects help-seeking in Symptom Perception Theory (Moller-Leimkuhler, 2002; Gijsbers Van Wijk and Kolk, 1997; Leventhal et al., 1980).

Pregnancy can be distinguished from chronic illness in that it lasts for a defined period, and women are often perceived as 'well'. However, in pregnancy 'normalisation' could be seen among women in this PhD study as trying to protect their existing normal pregnancy, projected birth plans and their future plans of a normal life style with their new baby or babies. It could be argued that in some cases, women in the current study were unaware of the signs and symptoms of

pre-eclampsia, so did not recognise their deteriorating health or that normalisation occurred.

This was more apparent in women who were low-risk at booking and had high expectations of a natural birth. Others, even though they were advised to have a medical intervention for their baby's and their own safety, bartered to try keep the pregnancy pathway 'normal', to avoid missing important family events or for practical reasons such as child care. One woman who was on holiday normalised severe signs and symptoms of pre-eclampsia as she preferred to wait until she was near her own hospital rather than go to a new hospital that they happened to be near to. These factors can also be related to candidacy; as mentioned earlier, women adopted multiple candidacies and at times this could be seen as being a barrier to seeking help i.e. delaying access to the services and also resisting care pathways and delaying possible treatment.

Delaying treatment is not new to help-seeking literature and has been researched by several authors in general healthcare for many disorders (Smith et al., 2005; Stack et al., 2012; Horne et al., 2000; Burgess et al., 2001; Dubayova et al., 2010; Walter et al., 2012; Mackintosh et al., 2012). Reasons as to why some women with pre-eclampsia delayed seeking help were similar to findings of studies of patients' experiences of help-seeking for acute illnesses such as stroke and heart attack. Some of the women in the study did not seek help as their symptoms did not 'match' those they were aware of, for example, experiencing diarrhoea and vomiting and extreme exhaustion. This is similar to the study cited in Chapter 3 where patients delayed seeking help for stroke and heart attack symptoms as they perceived that their symptoms did not match those traditionally advertised in public health campaigns (Henriksson et al., 2012; Greenlund et al., 2004). Another stroke study found that some patients perceived their symptoms to be mild and not readily recognised as stroke, and so did not consider calling the emergency services (Mackintosh et al., 2012). This was again similar to women in this PhD study, particularly those classed as low-risk who did not seek help even when signs and symptoms were severe. Leventhal et al (2004) also found that symptoms of

deteriorating health may be misleading in terms of their diagnostic value as severe symptoms may be associated with a mild illness and yet a more serious illness may manifest itself without obvious signs and lead to unnecessary delays in seeking help (Leventhal et al., 2004).

An additional reason why women delayed help-seeking was women's own perceptions of risk. A meta-synthesis of risk perception in women with high-risk pregnancies concluded that women use multiple sources of information to determine their risk status (Lee et al., 2014). This is concurrent with this PhD study where women used the internet, friends and family and healthcare workers as sources of information. This synthesis highlighted that while women were aware of the risk imposed by their pregnancies they did not perceive risk in the same way as healthcare professionals. At times this meant that women did not follow all medical recommendations (Lee et al., 2014).

Risk perception among pregnant women was explored in a qualitative study from Canada (Heaman et al., 2004). This was a descriptive qualitative study in which women described factors they considered in making personal risk assessments. Of 205 women in the study, half (n=103) had pregnancy complications, while the remainder (n=102) had no known complications (Heaman et al., 2004). They identified how these perceptions impacted on subsequent health-related behaviours. Several differences were found between the two groups, most significantly that women with complicated pregnancies voiced greater risk perceptions and identified specific and real risks (Heaman et al., 2004). They focused on their symptoms and their medical diagnoses. This is similar to the findings of this study where women at high risk were more likely to identify signs and symptoms of pre-eclampsia. Another study of 21 women also found that women identified as high-risk and referred to hypertension clinics in the antenatal period had different reactions to being deemed at risk (Jackson et al., 2006). For example, some women accepted that their pregnancy required closer assessment, but others had difficulty accepting their changed identity or recognise the reason for the referral as legitimate (Jackson et al., 2006). Diagnosis left many women

feeling more anxious when their identity changed from being 'normal' to being classed as an individual with a condition (Jackson et al., 2006). This could also be perceived as 'normalisation'. It was also a finding of this PhD research, that some women accepted their diagnosis of pre-eclampsia whereas others did not, and this affected their help-seeking behaviour. Again, Jackson et al.'s (2006) study was not about help-seeking or signs and symptoms of pre-eclampsia. Interestingly, Pozzo et al. (2010) found that even though women may not adhere to recommended treatment they still wanted to be informed of the risks they were facing.

Another finding of this PhD study was that women and healthcare workers are likely to have different views of their risk or treatment pathways, which may cause tension between the health care workers and women.

When looking through the lens of 'identification of candidacy' from the women's and families' perspectives, facilitators to help-seeking could be seen to be: knowledge of signs and symptoms gained from healthcare workers, friends and family or the internet; previous experience of pre-eclampsia or knowing a family or friend who had had it; additional safety concerns for the unborn baby; and use of self-monitoring. Barriers were seen to be normalisation of signs and symptoms, and categorisation from booking and throughout the care pathways, leading to knowledge given to some high-risk women but not low-risk women.

Women's concern for the baby also affected their negotiating; this included accepting medicalisation even when they felt well and did not believe they had pre-eclampsia. For example, one of the low-risk women who was routinely identified at an appointment when her blood pressure was found to be high, but felt well and so did not feel the need to be admitted. She also did not want to miss her own wedding the next day. She accepted admission as she did not want to put her baby at risk. Many other women also accepted treatment for the baby even though they were not sure they had pre-eclampsia. When using the candidacy framework in the pregnancy setting it may be useful to have another dimension added specifically for the baby.

## 8.2.5 Organisational constraints

In line with other researchers' findings, organisational constraints affected women's candidacy with pre-eclampsia in both antenatal and postnatal periods. For example, women who had a diagnosis of pre-eclampsia often experienced long waiting times on antenatal wards before being assessed and treated, as they were waiting for beds or midwives to be available. This was similar to other researchers who used candidacy to explain help-seeking trajectories in Chapter 3 i.e. long waiting times and services perceived to be hostile or insensitive (Chase et al., 2017; Normansell et al., 2016). Although some women and their families sometimes spoke up, asserting their candidacy as they were concerned for their safety with long waits, others accepted the waits and were more passive in understanding how the busyness of units impacted on timeliness of care.

Mackenzie et al. (2013) highlighted the dynamic nature of candidacy theory as service users often needed to continually renegotiate their way during their medical journey. They highlighted the importance of negotiations at the micro, meso and macro contexts between service users and healthcare workers. They suggested that interactions between service users and healthcare workers, the organisation and national and political contexts, affected candidacy (Mackenzie et al. 2013a). This dynamic nature was also seen for women with pre-eclampsia.

Women used candidacy to negotiate throughout the pregnancy pathway using facilitators such as knowledge, categorisation, signs and symptom perception and self-monitoring. Barriers to help-seeking also repeated throughout the stages and included factors such as sign and symptom perception, categorisation, normalisation, trade-offs and organisational restraints. Candidacy Theory may not be practical to use to gain insight from health workers' perspectives, so Lipsky's Street-level Bureaucracy Theory (SLB) will be used in conjunction with it.

## 8.3 Street-level Bureaucracy (SLB)

What was missing from many of the help-seeking models, including candidacy, was how healthcare workers responded and what contextual factors affect this. Another theory was needed to illuminate factors affecting healthcare workers' responses as candidacy has previously been used to understand negotiating and access to care from the service users' perspectives, not healthcare workers' perspectives. Lipsky's social theory of Street-level Bureaucracy (SLB) (Lipsky, 2010) has provided insight into how healthcare is organised and delivered and how the drivers for efficient processing of service users through a system conflicts with the individual front-line worker's desire to provide person-centred care, often leading to healthcare workers having to use their discretion on how to deliver individualised care (Evans, 2011).

### 8.3.1 Clinical resources versus clinical need

This study found that healthcare workers' responses were often influenced by the 'conflict' between available resources and the clinical priorities of those needing care. Often healthcare workers were unable to respond immediately to women and their families due to high clinical workloads. Healthcare workers were often placed in difficult situations having to reprioritise care, as new higher priority clinical cases came in. How healthcare workers juggled these conflicts could be seen to reflect Lipsky's SLB Theory.

Lipsky stated that demand from clients will always outstrip supply in human service organisations with finite resources (cost, time or service access), and as a result employees must resort to efficient 'mass processing' of excessive client caseloads (Cooper et al., 2015; Lipsky, 2010). In this thesis specific examples occurred not only in categorisation of patients (see section 7.3.1) and the amount of information given, but also that healthcare workers acted as 'street-level bureaucrats', consistently triaging and reprioritising as women with perceived higher priorities for clinical care needed treatment regardless of the setting of care. Thus following Lipsky's theory healthcare workers "*are expected to be advocates to use their*

*knowledge and skills and position to secure the best treatment or position consistent with the constraints of the service*" (Lipsky, 2010 p.27). However, by reprioritising one woman, inevitably other women's treatment was delayed.

This was observed most often in this PhD study by women who reflected on the care they received in walk-in centres and on antenatal wards. These places were where women often experienced the most delays in treatment, as for many it was the place they received their initial diagnosis and then they sometimes had to wait to be admitted to the hospital and/or commence immediate treatment. Finlay and Sandall (2009) drew on Lipsky's SLB Theory to understand how midwives managed competing demands of delivering a personalised midwifery service within a bureaucratic organisation by looking at standard care and caseload care models of midwifery care; the findings were similar to those of this PhD study. They also recognised the conflict between meeting the needs of the organisation and the needs of the women, especially for the standard care model (Finlay and Sandall, 2009). They noted that street-level bureaucrats "*must find a way to resolve the incompatible orientations towards client-centred practice on the one hand and expedient and efficient practice on the other*". Staff who did not follow the continuity of care model allegiance were closer to the organisation and its need to ration available recourses than to their individual clients (Finlay and Sandall, 2009).

Hospital midwives who were interviewed for the current study delayed transferring women to manage the workflow from walk-in services where they had been assessed, to the antenatal wards so that ward staff were not overloaded with additional work in line with organisational regulations. This reflected the finding of Penn-Kekana et al. (2004) where the researchers found the multiple demands of implementing a plethora of new reforms took up their time and led to healthcare workers prioritising and attempting to implement the most recent policy, or which policy was to be inspected next; subsequently, managers demands were prioritised over patients' quality of care (Penn-Kekana et al. 2004). Thus in this PhD study and Penn-Kekana et al.'s (2004) study, while implementing hospital regulations, patient quality of care was affected. This contrasted with Lipsky's view, where

front-line providers fail to implement reforms that do not conform to their sense of what is right and possible (Lipsky, 1980).

Healthcare workers also found balancing clinical risk versus clinical need difficult to manage emotionally and at times described being angry at not being able to provide services in a more timely way. This reflects Lipsky's theory where healthcare workers tried to balance of the need of the individual to the organisational resources, making it difficult to give individualised care. Greenhalgh et al.'s definition of individualised care, i.e. "*real evidence-based medicine has the care of individual patients as its top priority, asking 'What is the best case of action for this patient, in the circumstances, at this point in their illness?' It consciously and reflexively refuses to let process (doing tests, prescribing medicines) dominate outcomes (the agreed goal of management in an individual case)*" (Greenhalgh et al., 2014 p.3) is virtually impossible to deliver. In line with Greenhalgh's definition of individualised care and Lipsky's theory it can be seen in this PhD study that the providers' desire to offer personalised care clashed with organisational objectives, and the difficulty of processing workflow often led to poor quality care, affecting both women and their families, and healthcare workers.

An important new finding of this research is the rationale healthcare workers gave when their desire to give personal care was compromised due to high workloads; a few staff members felt that in order to comply with the busy workload of the organisation they felt pressure to delay escalating care for management of possible medical complications, so that additional work was not created. This might mean withholding information about a high blood pressure. The junior midwife felt there was a pressure to keep women's care pathway 'normal'. Three junior healthcare workers mentioned this, and possibly there could be other interpretations of these findings e.g. power dynamics. Healthcare workers described how at times they were encouraged to try to keep women categorised as low-risk so workloads would be reduced. This left healthcare workers feeling their own clinical skills were undermined by the organisation's needs which were deemed more important than



their own assessment of the situation. Here pressures to keep the care pathway of women 'normal' were prioritised over safety.

Lipsky's theory does not address the emotional impact on individual staff who described that their own clinical skills were undermined in order to support the organisation. To achieve job satisfaction, some looked at where they could provide client-centred care. Interestingly, the findings contrasted with Walsh et al.'s (2006) ethnographic study in the UK (see Chapter 3) which found that in contrast midwives believed they had real autonomy and exercised it every day and were happy working within their organisation (Walsh, 2006).

Lipsky's SLB Theory informs understanding as to why staff prioritised care and information sharing due to lack of time and busy workloads, but there may be other explanations. By selecting who should and shouldn't receive information, and how, about pre-eclampsia could also be seen to be an inadvertent misuse of power by healthcare workers i.e. healthcare workers often used strong language at diagnosis especially when women appeared wanted to continue on the 'normal' birth pathway such as having a homebirth.

### **8.3.2 Knowledge and categorisation**

Many women in the current study identified being 'categorised' as high- or low-risk in their booking appointment as a problem they had experienced e.g. healthcare workers chose not to offer information on signs and symptoms of pre-eclampsia to women defined as low-risk at their booking appointment as they did not want to scare them, but did offer information to women considered to be high-risk as they felt they were more likely to develop pre-eclampsia. All the women in the study had had pre-eclampsia and so had the benefit of hindsight. The health professionals concurred that the content of information on risks, signs and symptoms of pre-eclampsia were tailored to reflect the outcome of their first assessment of women at booking.

The law on information sharing in the UK has changed since the Montgomery case in 2015. The law now requires a doctor to take "*reasonable care to ensure that the*

*patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments.”* (Montgomery v. Lanarkshire Health Board, 2015). This contrast with the Bolam test where clinical decision-making asks whether a health professional’s conduct would be supported by majority peer review (Rogers v. Whitaker, 1992). By following this new guidance the emphasis is on the health professional to decide what is reasonable (Sokol, 2015).

Concerns about the 2015 case were raised by Montgomery and Montgomery (2016) that this new law promotes a disproportionate amount of power to the medical profession to decide what is right for each individual patient without actually asking the patient what they want to know. This appears to concur with the findings of this research where women were regularly given information at the healthcare workers’ discretion, compared with what the women retrospectively said they would have wanted.

This new law and the results of this study could impact on how healthcare workers share information with women and their families regarding pre-eclampsia, where clinicians decide what to share with individual women rather than asking them. In addition, many women may choose not to know.

Another reason for the difference in information sharing may arise from the content of relevant NICE guidelines where more emphasis is placed on providing information on signs and symptoms of pre-eclampsia for women with hypertensive disorders compared with women with uncomplicated pregnancies (NICE, 2017; NICE, 2016). NICE guidance for women with hypertensive disorders, for example, is more specific and recommends that treatment and care should take into account women's needs and preferences. This includes that *“pregnant women should be made aware of the need to seek immediate advice from a healthcare professional if they experience symptoms of pre-eclampsia.”*

This contrasts with the NICE guidelines for the antenatal care of women with uncomplicated pregnancies. Recommendations aim to ensure that pregnant women are offered regular check-ups, information and support (NICE, 2017). The

guidelines also recommend that pregnant women should be offered information based on the current available evidence together with support to enable them to make informed decisions about their care, but there is no specific advice about ensuring women are offered information about signs and symptoms or the onset of potentially serious health problems in pregnancy, with the exception of the NICE postnatal guidelines where women are encouraged to look out for signs and symptoms of pre-eclampsia and sepsis (NICE, 2013). Interestingly, none of the staff interviewed for this study cited compliance with NICE guidelines as informing the content of information they shared with women and their families, or mentioned the impact of the Montgomery decision on this.

The reasons healthcare workers gave for not giving all women information on pre-eclampsia could be explained by SLB Theory, where often they referred to time constraints in busy clinics and the importance for some women of focusing on 'normality'. But other reasons were also given, as in this research; healthcare workers were often concerned about scaring and overburdening women with information on pregnancy complications and thus tried to give individualised information depending on women's characteristics, such as giving less information to women who were anxious. Other healthcare workers contradicted this and described busy medical settings and many other pregnancy disorders they would need to discuss if they were to offer the full range of information on possible pregnancy complications to every woman. This dilemma was mentioned in all settings including community antenatal clinics, the hospital pregnancy walk-in service, antenatal wards and postnatal wards. No staff mentioned the difficulty of offering information during labour and birth, where normally care is delivered one-to-one. This again supports SLB Theory where healthcare workers tried to preserve time by giving less information to speed up workflow, thus compromising the safety of women and their babies.

SLB Theory could be applied to exploring factors affecting healthcare workers' responses include the difficult balance between giving information and not wanting to scare women, and between keeping to hospital targets and meeting clinical

needs when resources were low. Interestingly, this could be seen to be similar to Lipsky's theory where healthcare workers have to make care choices at the front-line to fit both the organisation and the individual service user, often compromising both.

## **8.4 Conclusion**

The empirical evidence suggested that delays in help-seeking for signs and symptoms of pre-eclampsia is influenced by a complex interaction of social, clinical, psychological and organisational structural factors. Not one factor was shown to be dominant. This PhD contributes important insights into access to and delivery of maternity services for pre-eclampsia, and could help inform the improvement of services both antenatally and postnatally.

The findings of this PhD concurred with other studies that there is a lack of knowledge and understanding of pre-eclampsia, but there were also significant new findings. These include: the use of negotiation and candidacy to help seek; categorisation at booking; normalisation of symptoms by women and their families and sometimes healthcare workers; the role of self-monitoring; and the effect of organisational workflow pathways on help-seeking. Candidacy Theory could be used to explore the help-seeking trajectories of women with signs and symptoms of pre-eclampsia; however, when using the framework for pregnancy it may be useful to add a dimension for the baby specifically, as often concern for the safety of the baby influenced the mother's reason for candidacy as well as many of the other dimensions. Candidacy Theory was suitable for explaining help-seeking and negotiation from the women and families' perspectives but not what affected the healthcare workers' responses.

Factors affecting healthcare workers' responses were: information sharing; difficulty of diagnosing pre-eclampsia; responsibility and self-monitoring; clinical need versus clinical availability; and relationships and continuity of care. Individualised care was often compromised as healthcare providers made front-line

care choices to meet both the organisation's and the individual service user's needs, which resonates with Street-level Bureaucracy (SLB) Theory.

## **8.5 Strengths and limitations of the study**

The literature searches in the initial chapters of the PhD confirmed the limited research which had explored the potential for women, their partners or other family members, to raise concerns regarding the symptoms and signs of onset of pre-eclampsia, or what prompted an effective response from the healthcare workers to whom they reported their concerns. The strength of this is that the study addressed a clear research gap using the principles of a narrative approach to explore the experiences of women, their families, health care workers and other stakeholder representatives to reveal factors that affected women's help seeking.

By selecting the principles of a narrative approach, participants were encouraged to freely describe their experiences without the researcher constraining the interviews with structured questions. This allowed new data to emerge from the findings not previously identified in the literature reviews, contributing to findings from previous research that has identified that a narrative approach can be used to help understand and unpick the complex care pathways women experience and the stories can be processed and used as examples to change practice (Holloway and Freshwater 2007b; Berlinger, 2003; Miller, 2000).

As this was a single site study, undertaken by a single doctoral researcher, there are limitations with respect to the potential generalisability and reliability of the findings. In qualitative research there is much debate as to whether it is valid to draw wider inference from a single study depending on whether it had any reality beyond the context in which it was derived (Ritchie and Lewis, 2007). However, the site chosen was carefully selected as it served a diverse population including women from different socio-economic, cultural and ethnic groups, parities and ages. To compensate for potential recruitment bias and enhance representational generalisability, purposive heterogeneity sampling was used (Teddlie and Tashakkori, 2009). By using this approach a greater depth of data were acquired

from the carefully selected cases (Teddlie and Tashakkori, 2009). In addition, reoccurring themes emerged from the data suggesting that the sample size was sufficient.

A different approach may have been useful for recruiting family members as only five were recruited. For example, asking the research midwives to recruit partners in the hospital at the same time they asked the women participants could have made a difference. Healthcare workers were also very difficult to recruit. The reason they gave for declining to participate was lack of time. This small data set made it difficult to compare if different healthcare workers i.e. doctors and midwives may have had different views i.e. when women used of self-monitoring methods to seek help.

A strength of the study, to mitigate against recruitment of women and their families and health care workers being from one site, five representatives from relevant charities across the UK were interviewed. These organisations represented a wide range of maternity service users and provided expert knowledge of social and medical complexities regarding pre-eclampsia. These representatives were involved to give an understanding of the scale and nature of the problem and provide a follow-up of the interviews from stages 1 and 2. In their own admission they did not represent BME women or vulnerable women identified by NICE Pregnancy and complex social factors (NICE 2010). This was a weakness of the study and maybe charities representing specific BME women or women with complex social factors could also have been included.

This continual involvement of PPI and peer review was a strength of the study and a validation of the findings. This fits with the current INVOLVE definition of research for patient benefit which recommends that research should be “with” or “by” people who use services rather than “to”, “about” or “for” them (INVOLVE, 2012). An example is when the early findings were presented to PPI representatives including meetings of the local Maternity Services Liaison Committee, National Childbirth Trust (NCT) and the local study site Pre-term Birth Studies Panel.

There was a potential for bias as the being a researcher, a midwife and a mother there may have been subconscious bias. To mitigate this the researcher's reflexivity was essential throughout the research process to increase methodological rigour .i.e. the researcher was conscious of her own prejudices and assumptions and attentive to sources of bias (Lynch, 2000).

The researcher was also mindful of the potential for 'co-production' of the story during the interview i.e. the participants may have been influenced by the presence of the researcher and how the researcher interprets their stories (Riessman, 1993). An example was extra "nodding" during interviews with health care workers when they were telling stories about busy postnatal wards. After the first interview the researcher minimised the "nodding".

To strengthen the study design it was informed by theoretical approaches to enhance theoretical generalisability beyond the descriptive. These were the Symptom Perception Theory" (Moller-Leimkuhler, 2002; Gijsbers Van Wijk and Kolk, 1997); Candidacy Theory (Dixon-Woods et al., 2006; Dixon Woods et al., 2005) and to understand factors affecting healthcare workers' responses, Lipskys' social theory of Street-level Bureaucracy (SLB) (Lipsky, 2010). Thus theoretical generalisation took place at the level of categories, concepts and explanations (Ritchie and Lewis, 2007 p.269). See Discussion.

## **8.6 Conclusions and implications for clinical practice, policy and further research**

The findings in Chapters 6 and 7 suggest a range of implications for clinical practice, policy and future research for women and their families, health care workers and how these organisational factors affect help seeking. See below for further explanation.

### **8.6.1 Implications for clinical practice and policy**

This study identified several implications for clinical practice arising from the narrative synthesis, empirical findings and from exploring how help seeking

theories contextualised these findings. A key finding was that all women and their families need information on signs of pre-eclampsia in early pregnancy to inform timely help-seeking, and healthcare workers need training to deliver information.

All the low-risk women interviewed were unhappy with the lack of information and would have liked to have been given more information about pre-eclampsia. NICE guidelines may need updating so that all pregnant women, both low and high-risk, receive information on signs and symptoms of pre-eclampsia (NICE, 2016; NICE, 2017). The Nursing and Midwifery Council (NMC) will be consulting on a new draft of educational standards for registered Midwives in 2019, with the aim of publishing the new Educational Standards in 2020, it will be important to highlight the findings of this research to this consultation e.g. of how categorisation can impact on information given to women and also the research highlighted the importance of tailoring information to individual women's needs.

Another important finding was how other social and psychological factors apart from knowledge impacted on help-seeking. There needs to be an awareness of social and psychological factors and a greater emphasis on individualised care to meet women and family individual needs. Family members were often involved in women's help-seeking trajectories and rarely knew about pre-eclampsia before its onset. Friends and family would benefit from antenatal information regarding pre-eclampsia, as well as the pregnant woman. Antenatal classes could be more tailored and at suitable times for family members to attend.

The range of signs and symptoms women experienced prior to being diagnosed with pre-eclampsia go beyond the traditional six documented by the Royal College of Obstetricians and Gynaecologists (RCOG) and National Institute for Health and Care Excellence (NICE) (NICE, 2017; NICE, 2016; RCOG, 2014). Some women did not experience any signs and symptoms. The advice offered to women about the onset of pre-eclampsia should be reviewed so that women, their families and healthcare workers are aware that some women develop pre-eclampsia with no prodromal signs, emphasising the importance of attending regular antenatal appointments and possibly a need for self-monitoring.



An interesting finding of the study and an implication for practice and policy was the number of women (mainly self-initiated and self-taught) who used blood pressure reading and other self-monitoring initiatives such as their weight gain, urinalysis, fetal growth and fetal movements to identify candidacy and to “navigate” the services. Many women with a higher level of education used tools in this way. This bartering was used both to escalate and to delay treatment. Many of the health care workers were concerned about this and how this would work if used routinely in clinical practice. They were concerned about the level of training women would need and the cost and reliability of the blood pressure machines.

Another finding was that even though all the women and babies survived in this study, reflecting MMBRACE mortality statistic on maternal death and pre-eclampsia, many of these women had “near misses” and we do not know the impact this may have had on them in the future or their babies’ futures. MMBRACE are planning to include morbidities online in the future. This study has indicated that this may be important for pre-eclampsia.

### **8.6.2 Implications for further research**

In the study design women were only interviewed once in the postnatal period when they were back at home. There may have been different findings if women had been interviewed at several different points in their journey. Serial qualitative interviews have been used by researchers in the past to understand patients’ evolving experiences and it is suggested that this could give a much better picture of their experience than single interviews (Farrall et al. 2016; Murray et al. 2009).

In addition only women who had experienced pre-eclampsia were interviewed which showed that women were not happy with the level of information received. It is possible that women who do not develop pre-eclampsia are happy with the level of information they receive, this is could be an area for future research

The research highlighted the importance of tailoring information to individual women’s needs. One idea for health care workers would be that as they are taking blood pressure and checking urine at each visit that could be when the inform

women about pre-eclampsia. This would prevent more time being need. It could be a pilot study. Further research may be needed as to how to implement this.

Friends and family would benefit from antenatal information regarding pre-eclampsia, as well as the pregnant woman. Antenatal classes could be more tailored and at suitable times for family members to attend. Further research may be needed as to how to implement this.

The research also highlighted how women did their own research on the internet for information either prior diagnosis or post diagnosis. One possible intervention could be the development of an APP carefully designed to give only as much information as the women or their family members wanted. This could be a useful tool for midwives to be able to give to all women at booking. A future pilot study could be the designs of the APP and use of the APP. It would be important to involve other stakeholders such as the RCOG, RCM, APEC and other charities

Further research into potential benefits or disadvantages of all women routinely self-monitoring is needed and how health care workers could be more integrated with this, possibly a pilot co-design project could be of use. Further research is needed on how effective self-monitoring is to gain access to health care and also how all women could use it not just women with higher literacy levels.

Women, their families and healthcare workers experienced the prioritising of care versus the clinical availability of resources as often difficult to manage.

Explanations of how triage works may benefit women and families. This needs further investigation.

Despite NICE guidance for hypotensive disorders (NICE, 2010) optimal discharge planning for women with pre-eclampsia was poor and many of the women and healthcare workers felt this was an area where care became uncoordinated and difficult for women to help-see. Better implementation of this guideline is needed and more implementation research could be of use.

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## 10. Appendices

### Appendix1 BMC pregnancy and Birth Published Article

#### RESEARCH ARTICLE

#### Open Access



# A narrative synthesis of factors that affect women speaking up about early warning signs and symptoms of pre-eclampsia and responses of healthcare staff

Wendy Carter<sup>1,3\*</sup> , Debra Bick<sup>2</sup>, Nicola Mackintosh<sup>1</sup> and Jane Sandall<sup>1</sup>

#### Abstract

**Background:** One of the challenges for treating pre-eclampsia and preventing further deterioration is determining how best to enable early detection. If women or their partners and families are able to raise early warnings about potential signs and symptoms of pre-eclampsia in pregnancy, birth and in the postnatal period, women may be able to receive earlier intervention to prevent severe pre-eclampsia from developing. The aim of this study was to improve understanding of factors affecting the ability of women to recognise symptoms and signs of pre-eclampsia/ eclampsia and seek appropriate medical help and factors affecting health care professionals' responses to women and their families who 'speak up' about early warning signs and symptoms.

**Methods:** A narrative synthesis was conducted of evidence relevant to address the research question. The following electronic data bases were searched for qualitative studies which met inclusion criteria from January 1980 to April 2016; Medline, CINAHL, HMIC, PsycINFO, Embase, BNI, ASSIA, Scopus, Maternity and Infant Care, Web of Science, Google Scholar, Cochrane, JBI and IBSS with the support of an Information Service Consultant.

**Results:** Following thematic analysis, three themes were identified; 1: Women's understanding and knowledge of pre-eclampsia/eclampsia; 2: Factors affecting help seeking behaviour from perspectives of women and their families; 3: Factors affecting staff response. There was widespread lack of knowledge and understanding of signs and symptoms of pre-eclampsia/eclampsia among women and their families, with some women not exhibiting signs and symptoms of pre-eclampsia or unable to distinguish them from 'normal' pregnancy changes.

**Conclusions:** Women and their families not only need to be made aware of signs and symptoms of pre-eclampsia/ eclampsia but also require information on the most effective ways to seek urgent medical assessment and care. Some women did not experience prodromal signs and symptoms, which raises concerns about how women and families can detect early onset, and is an issue which needs further exploration. There is very limited research exploring clinical staff response to women who raise concerns about their health when experiencing symptoms and signs of pre-eclampsia/eclampsia with further research needed if safety and quality of care are to be improved.

**Keywords:** Pre-eclampsia, Narrative synthesis review, Midwives, Help seeking

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## Background

Pre-eclampsia is a major obstetric problem affecting 2–8% of pregnancies and is a leading global cause of maternal and perinatal mortality and morbidity [1]. It is a pregnancy specific disease characterised by de-novo development of concurrent hypertension and proteinuria, sometimes progressing into a multisystem disorder [1]. The potential adverse perinatal outcomes include intrauterine growth restriction, preterm birth and fetal death [2]. If untreated, pre-eclampsia can develop into eclampsia when maternal seizures develop [3]. HELLP Syndrome (Haemolysis, Elevated liver enzymes and Low Platelet) is regarded as a variant of severe pre-eclampsia and can occur in 10 – 20% of cases with severe pre-eclampsia [4].

The incidence of pre-eclampsia and eclampsia varies internationally. Eclampsia is more common in developing countries than in high income countries [5]. For example, in Latin America and the Caribbean hypertensive disorders are responsible for around 26% of maternal deaths, whereas in Africa and Asia they contribute to around 9% of deaths [1]. The incidence of pre-eclampsia is reported to have increased in the USA, which may be related to an increased prevalence of predisposing factors such as chronic hypertension, diabetes and obesity [6].

For the purposes of this synthesis pre-eclampsia was defined as “a combination of a new hypertension and proteinuria and typically occurs after 20 weeks gestation” [7]. Severe pre-eclampsia is pre-eclampsia with severe hypertension and/or symptoms and/or biochemical and/or haematological impairment and eclampsia is defined as a convulsive condition associated with pre-eclampsia [7] which can also present for the first time in the postnatal period [8]. For purposes of brevity in the remainder of the paper the term pre-eclampsia should also be understood to include severe pre-eclampsia and eclampsia unless otherwise indicated.

One of the challenges for treating pre-eclampsia and preventing further deterioration is determining how best to enable early detection. If women or their partners and families are able to raise early warnings about potential signs and symptoms of pre-eclampsia in pregnancy, birth and the postnatal period, they may be able to receive appropriate intervention to prevent onset of severe pre-eclampsia from developing. Early warning signs of severe pre-eclampsia, which can deteriorate very quickly, include specific physical symptoms such as severe headaches that does not resolve with simple painkillers, problems with vision, such as blurring or flashing before the eyes, severe pain just below the ribs, heartburn that does not resolve with antacids, rapidly increasing swelling of the face, hands or feet and feeling very unwell [9].

Currently there are a limited number of strategies to help service users identify and seek help concerning a sudden deterioration in health, including pre-eclampsia. One exception is the NICE postnatal care quality standard [10] which recommends that all women are offered information on signs and symptoms of serious health problems within 24 h of the birth relevant to their own health and the health of their babies. This information should include prompts to enable women, partners and families to recognise serious health problems and when to seek urgent medical care [10]. A recent report which looked at implementation of the NICE quality standards on postnatal care found that 47% of mothers were unaware of signs of health deterioration in the postnatal period, despite the recommendations, and that around a quarter of women questioned were aware of signs and symptoms of health deterioration [11].

There is a limited amount of research regarding pregnant and childbearing women's involvement with promoting their own safety. However, in UK maternity care there is increasing evidence that a number of women and their families do not always feel listened to or receive an appropriate response from healthcare professionals [12–14]. For example, a [12] highlighted that concerns of women were not being listened to. It showed that out of a random sample of over 23,000 women who gave birth in February 2013, 19% felt their concerns during birth and labour were not taken seriously.

Another example cited from a recent report of the UK National Perinatal Epidemiology Unit (NPEU) found that of the women whose babies died before labour, only 57% felt listened to or their concerns taken seriously. Of the women whose babies died during labour, a quarter felt that staff communicated poorly, almost half did not feel listened to and around 10% reported rarely or never having trust or confidence in the staff caring for them during labour and birth. The most common finding among women and partners whose babies died before labour was that 72% recognised that something was wrong with changes in their babies' normal pattern of movement. When they were asked about raising their concerns to health care professionals, a third of women reported contacting a clinician straight away and 46% within 24 h, but only 57% felt listened to at this time and 39% felt confident with decisions made [14].

Patient involvement in safety of their own healthcare is an emerging field internationally. It has been highlighted by the World Health Organisation (WHO) who recognise that patients and carers are at the very centre of the quest to improve healthcare safety [15]. The Council of Europe and the World Alliance of Patient Safety have also recommended that patients



should be involved in reporting of incidents and safety management [16, 17].

This narrative synthesis examined the extent to which the available literature could inform a greater understanding of the experiences of women and their families who raised an early warning about potential symptoms and signs of pre-eclampsia, and the organisational response. The research question the review addressed was:

*"What are the factors that affect women and their families speaking up with early warning signs and symptoms of pre-eclampsia and what are the factors affecting health professionals' response?"*

## Methods

To develop a focused question which included women's, their families' and clinicians' perspectives and to facilitate the literature search, the SPICE (Setting, Perspective, Intervention, Comparison, Evaluation) Framework was used [18]. The SPICE Framework is adapted from the PICO (Patient problem, Intervention, Comparison and Outcome) Framework and was more appropriate for this study as it enabled inclusion of all the perspectives of interest. See Table 1 includes the search and selection strategy for further details.

A narrative synthesis approach was selected as it produces a systematic, transparent approach, with guidance on enhancing trustworthiness [19–22]. The approach aims to produce a textual, narrative understanding of findings from included studies conducted in different settings and contexts [23].

The UK Economic and Social Research Council (ESRC) methods programme guidance was used to reduce risk of bias [20]. It includes a general framework or toolbox of four components namely: developing a theory, delivering a primary synthesis of findings of included studies, exploring relationships in the data and assessing the robustness of the synthesis. For the purposes of this review we used tabulation and thematic

analysis to analyse the data. Thematic analysis incorporates aspects of the grounded theory approach which is the process of coding, sorting and organising data, but it does not include theoretical sampling ([24] p 265); [25].

Each paper was allocated a number. Other table headings included author, country, method, sample type and size and key findings, (which also took into account the authors' discussion points) and a quality score for each paper (Table 2). Themes were extracted and adjusted, merged or excluded using the principle of the constant comparison methods and "one sheet of paper" (OSOP) method [25, 26] by the first reviewer WC with full text papers (Table 2). Contradictions and relations between the themes were explored before a final list of themes and subthemes were agreed by discussion and consensus of all of the reviewers using the OSOP method to visually map out themes and subthemes [26]. (Table 2).

## Quality appraisal

There is considerable debate on whether or not concepts such as validity and reliability apply to qualitative research and if so how these could be assessed [27]. Cochrane methodological guidance for qualitative methods involves (i) filtering against minimum criteria, involving adequacy of reporting detail on the data sampling, collection and analysis, (ii) commenting on technical rigour of the study elements indicating methodological soundness and (iii) paradigmatic sufficiency, referring to researchers' responsiveness to data and theoretical consistency [27]. However, some authors consider that formal appraisals of quality may exclude some studies ranked as 'lower' in terms of technical markers of quality, but ratings may not be sufficient to invalidate the findings [28, 29]. To maximise the inclusion and contribution of a wide number of studies, a low quality threshold was set using Dixon-Woods et al's five point checklist for quality [30]. Research was included regardless of quality due to the difficulty of assessing this among of studies which used a wide range of methods.

**Table 1** SPICE framework search terms

SPICE acronym	Keywords	Examples of alternative words
Setting	Health Care Systems Caring for women with pre-eclampsia	Hospital, community care, accident and emergency, maternity ward, antenatal clinic, postnatal Clinic, labour Ward, delivery Suite, birth centre, alongside midwifery units, community clinic, GP surgery
Perspective	Pregnant women and their families and health care staff	Antenatal, postnatal, pregnancy, labour, birth, obstetric, childbirth/ midwives, obstetricians, managers, maternity support workers, partners, health care workers, women
Intervention	Speaking up about pre-eclampsia/Patient Participation in safety	Patient involvement, patient collaboration, patient partnership, patient centred care, decision making escalation of care, early warning systems, signs and symptoms, organisation, management, speaking up, seeking help, help seeking behaviour, rapid response,
Comparison	Health Care staff response	Communication, team work, listening, nurse patient relations, midwife patient relations
Evaluation	Women/families/health care staff response	Perceptions, thoughts, attitudes, behaviours

Table 2 Characteristics of included studies

Paper number	Reference and country	Aim and setting	Methods	Participants	Relevant findings	Quality scores
1	Brewer et al. 2015 [31] USA	To evaluate the extent to which the Pre-eclampsia Registry responded to narrative inquiries and to ascertain the depth of information related to patient education. Online USA	Online open ended questionnaire with free text format included for one question about patient education. Retrospective questionnaire.	807 participants, 301 provided a response for a total of 355 pregnancies.	Additional information for women with pre-eclampsia was identified by 241 participants. Themes identified included: • Symptoms • Definition of preeclampsia • Improved provider communication • Risk factors for preeclampsia • Postpartum preeclampsia • Closer monitoring • Psychological support • Complications • Dietary concerns	5
2	Harris et al. 2014 [39] UK	To investigate the potential psychological impact of providing pregnant women with formal risk information for an antenatal screening test for preeclampsia. One London NHS trust.	Cross-sectional semi-structured interview study of women who had first trimester preeclampsia screening test. Retrospective interviews at 16 weeks gestation.	15 primigravida women, who had high risk results and 5 with low risk results at 12 week preeclampsia screening.	Two types of coping typologies regarding risk information for preeclampsia: "Danger Managers" who were focused on risk that preeclampsia posed to them and exhibited information seeking, positive behaviour changes and cognitive reappraisal coping mechanisms. "Fear Managers" who had an external sense of control and focused on the risk that preeclampsia posed to the foetus and exhibited avoidance coping mechanisms. 3 others themes emerged, medicalising pregnancy, embracing technology and acceptability.	4,5
3	You et al. 2012 [36, 37] USA	To explore the extent to which pregnant women understand the symptoms and potential complications related to preeclampsia and to determine the factors that are associated with better understanding. A university clinic in USA	Face to face survey with one open ended question with free text.	Convenience sample of 112 women recruited between 18 and 40 weeks gestation. 110 completed survey.	The survey identified a poor understanding of preeclampsia with a knowledge deficit. Factors associated with a greater understanding of preeclampsia were higher literacy, multiparity, history of preeclampsia, a receipt of information about preeclampsia from a clinician or another source.	5
4	Vasconcelos de Azevedo et al. 2011 [38] Brazil	To understand the meaning of preeclampsia for pregnant and postpartum women. São Paulo health care professionals Antenatal clinic and admissions unit of a public maternity hospital	Word association test and semi structured interviews.	51 pregnant women, 10 postpartum women, 87 health professionals completed word association test. 18 women, 2 postpartum women and 20 health professionals were interviewed.	Thematic categories based on word association test and the interview were created to help the data analysis. The results together demonstrate that pregnant and postpartum women had no information about preeclampsia. The meaning of preeclampsia to pregnant and postpartum women were fear, risk, care, and life of information. For health professionals the meaning were care, fear, risk, high blood pressure, oedema and proteinuria.	4,5

Table 2 Characteristic of included studies (Continued)

5	Barlow et al, 2008 [38] UK	To document women's experience of admission to hospital with a pregnancy related complication, hypertension from their own perspective One UK Maternity Inpatient ward	Qualitative descriptive study semi structured contemporaneous interviews with women after sudden and unexpected admission with high blood pressure, and for some additional symptoms such as proteinuria and oedema.	12 women, two with diagnosis of pre-eclampsia at time of interview.	Search for meaning: 7 women had not noticed signs and symptoms and some felt frauds being admitted. 5 women had noticed not feeling well, reduced fetal movements and two had had previous pre-eclampsia and were anxious and uncertain. Attribution to causality: Some felt they had tried to relieve stress in their lives, so could not understand why their blood pressure had been raised, others described stressful events and felt this may have contributed to admission. Information needs: Women valued being told the truth about their care pathway with diagnosis but some women felt they were not given enough information and were reluctant to ask staff questions. They reported being anxious and scared. Inconsistent information from different staff members was noticed. Social factors: All women felt it important to have the support of their partner/husband and other family members. Seeing women go the delivery suite and to return with a healthy baby was reassuring whereas seeing women return for a caesarean with catheters and drips was seen as 'scary'.	5
6	Kalim et al 2009 [32] Bangladesh	To assess differences in knowledge and care seeking behaviour in two districts of Bangladesh, Jessore, a high performing district of the country with higher literacy levels and lower maternal mortality ratio in comparison to a lower performing district of the country, Sylhet.	Mixed qualitative methods including free listing, rating exercises, hypothetical case scenarios and in depth interviews exploring the most commonly perceived complications, their relative perceived severity, knowledge of about signs and symptoms, care seeking behaviours related to PPH and eclampsia. Retrospective interviews at unknown time limit after event	118 women in total partook in studies, 40 regarding danger signs and care seeking for pre-eclampsia.	For women in low and high performing districts performing districts identified both PPH and eclampsia as life threatening complications. Understanding and knowledge in both districts women appeared to have a basic understanding of how to treat complications and where and were to take women for treatment, however in real life case studies there were major differences between their understanding to the conditions and care seeking behaviours in response to both PPH and eclampsia which could contribute to the high rate of maternal deaths associated with both conditions. Social and economic disparities affecting help seeking behaviour: There were differences in care seeking practices in the two districts possibly reflecting social cultural differences, disparities in economic and educational opportunity and discrimination in the availability of care.	4

**Table 2** Characteristic of included studies (Continued)

7	Lima de Souza et al 2007 [33] Brazil	To analyse maternal experiences of pre-eclampsia pregnancy with premature birth at a neonatal intensive care unit. State Hospital specialising in high risk pregnancies Brazil.	A qualitative study using focus group technique of women who had experienced pre-eclampsia with a premature birth. Retrospective focus groups whilst babies were still inpatients.	28 women who had experienced pre-eclampsia in pregnancy with a premature birth.	Themes included information on pre-eclampsia during prenatal care, experiences with a child in NICU, mother's perception of NICU professional attitudes. Information about pre-eclampsia it emerged from interview that women were unaware of pre-eclampsia which may have contributed to deficient preventative care and even to early hospitalisation. They only became aware after hospitalisation or by imminent premature delivery. Women feared their death or of losing their child. Mothers experiences with a child in NICU. First visit was often associated with shock, sadness and despair. During NICU daily routine difficulties were reported on not being able to hold child and seeing intensive treatments. Conflicts arose between home and hospital activities. Women also discussed joy of bonding with the child when first held their babies and when phototherapy and IV tubes were removed. Mothers perceptions of NICU professional attitudes Difficulties were identified regarding for caring the child in the neonatal care unit accentuated by communication flows between health professionals and users.	5
8	Macgillivray et al 2004 [34] Jamaica	To assess the efficacy and acceptability of a patient held pictorial card aimed at raising awareness and appropriate health seeking behaviour response to prodromal symptoms of imminent eclampsia. Antenatal clinics in Jamaica.	Survey and contemporaneous and retrospective unstructured face to face interviews with staff and eclampsia cases postnatally. Time scale not given when interviews took place.	192 mothers were surveyed before distribution of maternal pictorial card with pre-eclampsia symptoms, and 134 after. 3 women were interviewed who had eclampsia after card distribution. 18 health care workers were interviewed in five antenatal clinics and obstetric team in a hospital.	Survey showed a mother's awareness and response to symptoms improved significantly with use of pictorial information cards, posters and education of signs and symptoms of pre-eclampsia and there was a significant drop in eclampsia incidence. Post education programme there were 3 cases of eclampsia noted: Case 1 had not received the card at her antenatal clinic and had not seen a poster. Case 2 had a card and recognised the symptoms but went to her community health neighbour next door, delayed going to hospital and consulted. Case 3 was a young teenager who reported symptoms to the high risk clinic but was told to bed rest and return again in 1 week. At the time the condition of the referral hospital were overcrowded. Interviews with health care workers identified that they felt the card had enabled mothers to recognise symptoms that should be acted upon and had the	4.5



**Table 2** Characteristic of included studies (Continued)

9	Harrison et al, 2003 (40) Canada	To examine women's experiences of and satisfaction with their involvement with health care decisions during a high risk pregnancy. A Western Canadian City.	In depth open ended, semi structured interviews one month after birth with women who had experienced hypertension or threatened preterm delivery.	47 women, 16 women received in home care through a community programme, 15 hospitalised care and 16 women with in home care for index pregnancy and in hospital management of a previous pregnancy. 26 women had pregnancies threatened by preterm delivery, 17 had hypertension and 4 had hypertension and preterm delivery.	Women felt an increased feeling of responsibility for the health of their baby and themselves. They exhibited two approaches to decision making: active partners; and passive involvement. Women who wanted active involvement achieved it through one of 3 processes: struggling for negotiating or being encouraged. Women who wanted more passive involvement and women facing health crisis used the process of trusting the experts of nurses and physician. Women were satisfied if the care from the health professional was congruent with how they wanted to be involved in decision making.	5	unexpected benefit of giving a focus for discussion when the health care workers saw mothers in the antenatal clinic as well as improving their own knowledge of when to act.
10	Kitchner et al, 2004 (41) USA	To describe the experience of mothers whose pregnancies were complicated with HELLP syndrome and to determine if such experiences could be clustered by common themes from which a model could emerge. USA, home telephone interviews in urban and rural settings.	Descriptive home telephone interview qualitative study of survivors of HELLP syndrome. Retrospective interviews at 15 months to 13 years post delivery, with 2 years being the mean.	9 self-selected survivors of HELLP syndrome.	Participants expressed a loss of control and now knowing, 5 themes were identified: premonition, symptoms, betrayal, whirlwind and loss. Premonition: Just feeling something was not right. Symptoms: symptoms described as back pain, fatigue not feeling well, shortness of breath, abdominal pain, vomiting, severe upper quadrant pain. Betrayal: women reported being let astray and deceived and having their concerns viewed as worthless. They reported a sense of betrayal for trusted women, health care providers and their own bodies. Whirlwind: with recognition and diagnosis of HELLP syndrome physicians initiated an intensive whirlwind of activity to save mother and baby. Loss: loss and grief caused by HELLP syndrome delivery that was so different from the expected pregnancy outcome. Emotions expressed were fear of death, frustration, anger and guilt.	5	

The overall quality of papers was high (Table 2) supporting the robustness of the synthesis and findings. The lowest score, which was allocated to one paper, was 3.5/5 and five out of the 10 papers scored 5/5.

#### Search and selection strategy

Initially a systematic search of relevant literature was completed. Search strategies were constructed using key headings in SPICE to guide the review. Words from the research question which were adapted depending on the database. For example, a combination of free text and the database's own subject headings were used. The following electronic data bases were searched; Medline, CINAHL, HMIC, PsycINFO, Embase, BNI, ASSIA, Scopus, Maternity and Infant Care, Web of Science, Google Scholar, Cochrane, JBI and IBSS with the support of an Information Service Consultant from January 1980 to April 2016.

A typical strategy for this search was: ("Pregnant women" or "pregnant women and their families" or patients or childbirth or midwi\* or obstetrician\* or hospital\* or manager\* or "maternity support worker\*" or childbirth or "health care worker\*" or labour or families or partners) AND (preeclampsia or "pregnancy complications" or "obstetric complications" or "pregnancy induced hypertension" or "high risk pregnancy" or eclampsia or "maternal mortality" or "maternal morbidity" or deterioration) AND ("patient participation in safety" or "patient collaboration" or "escalation of care" or "patient centred care" or "patient involvement" or "patient choice" or "nurse patient relations" or "doctor patient relations" or "patient empowerment" or "early warning systems" or signs or symptoms or "speaking up" or "seeking help" or "help seeking behaviour") AND ("women's experiences" or "staff response" or perception\* or attitude\* or behaviour\*).

Other methods included hand searching references lists and citation tracking.

#### Inclusion criteria

English language studies were selected that used a range of qualitative approaches to capture evidence of the experiences of women and individuals in their immediate social network, such as their partner or other close family member, of pre-eclampsia and eclampsia.

#### Exclusion criteria

Quantitative studies were excluded as were mixed method studies if it was not possible to retrieve free text data. Non English language papers and grey literature was excluded.

#### Results

A total of 2395 records, titles and abstracts were screened for inclusion in the review, of which 2346 were

excluded as they were either duplicates or did not meet the inclusion criteria, leaving 49 articles remaining. Of these, 42 were excluded once the full article was assessed for eligibility, as they were either purely quantitative papers, mixed method studies where the results could not be separated or opinion pieces, leaving seven articles for inclusion in the review overall. A hand search of the reference lists identified two further studies and another was identified through citation tracking. Thus the total number of studies selected for the narrative synthesis was 10 (Fig. 1).

#### Data extraction and synthesis

Data extraction and synthesis are described in the methods section.

Table 2 summarises findings from the 10 papers. Three studies were from the United States, two from the United Kingdom, one from Canada, one from Bangladesh, two from Brazil and one from Jamaica. Topics covered by the studies are discussed in the narrative synthesis. Total number of participants involved in each study are also summarised in Table 2.

Table 3 summarises themes and subthemes identified during the narrative synthesis using the OSOP method [26]. By using allocated paper numbers (Table 2), Table 3 shows how data were retrieved for each sub-theme.

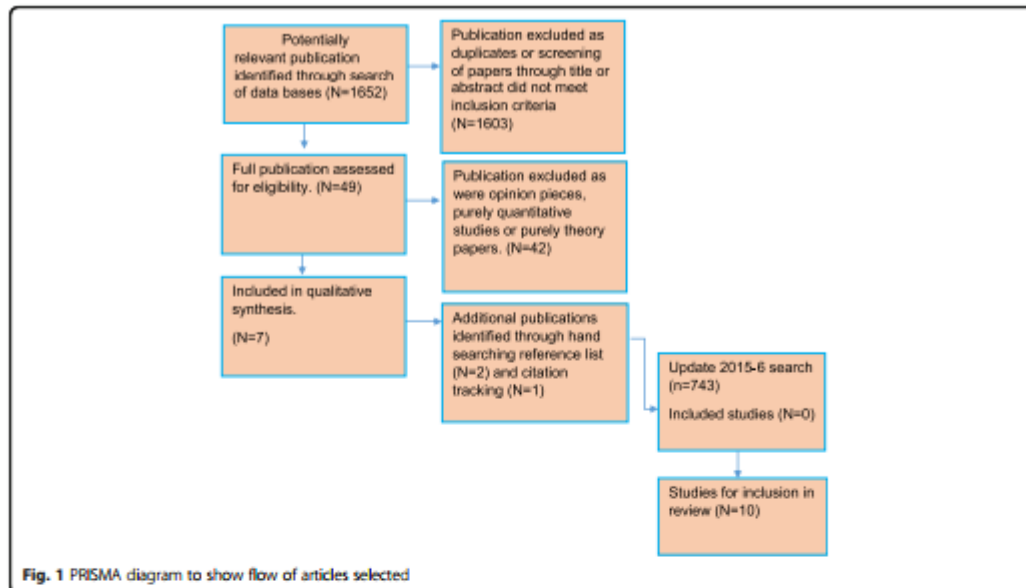
#### Narrative synthesis

##### *Theme 1: Women's understanding and knowledge of pre-eclampsia*

**Subtheme 1: knowledge** A common finding was that many of the women who participated in the included studies did not have an understanding of pre-eclampsia or its implications for their own or their babies' health. Many were also unaware of signs and symptoms of pre-eclampsia until after their initial diagnosis [31–37]. It was unclear if these women had any specific symptoms or signs and their lack of knowledge meant they did not appreciate their significance of these, or if they did not actually have any early warning of onset.

*"I didn't know. During prenatal care the doctor told me to rest and not to eat salt but she didn't say my pregnancy was high-risk" ([33] p 3)*

A lack of knowledge of pre-eclampsia among women who developed the disorder was reported from studies from several countries, including studies from Brazil, Bangladesh, USA, and Jamaica. For example in Brazil, all of the women interviewed in [35] study of the meaning of pre-eclampsia reported that they received almost no information about the disorder during their doctor's



appointment or during the period that they were hospitalised. Women reported that they wanted to know more about the development of pre-eclampsia, how to avoid it, and the consequences of the disorder. A second study from Brazil reflected these findings in cases where women who had had a preterm birth as a consequence of pre-eclampsia were unaware of the pre-onset of the disorder. It was postulated that this may have contributed to deficient preventative care and to early hospitalisation caused by the severity of their condition [33].

**Table 3** Summary Table of Themes and sub-themes

Theme	Subtheme including paper where data were retrieved
Theme 1: Women's knowledge and understanding of pre-eclampsia	Knowledge (1, 3–8)
	Absence or not recognising signs and symptoms (2, 5, 8–10)
	Range of information needs (1–3, 5, 8, 9)
Theme 2: Factors affecting help seeking behaviour from perspectives of women and their families	Emotions affecting help-seeking (2, 4, 5, 7, 10)
	Social, cultural and economic disparities (6, 9)
	Social networks influencing help-seeking (5, 6, 10)
Theme 3 : Factors affecting staff response	Practitioner-client communications and relationship (1, 4, 5)
	Not being taken seriously (4, 8, 10)

Similar findings were found in the UK, for example, women reported that admission to hospital had been sudden and unexpected following a routine antenatal clinic appointment due to high blood pressure and hypertension, and some had additional symptoms such as proteinuria and oedema [38]. This was also reported in studies from Brazil and the USA [33, 36, 37] further highlighting women's limited awareness of the signs and symptoms of pre-eclampsia.

Although most included studies highlighted a lack of understanding of pre-eclampsia or awareness of possible symptoms and signs, previous personal experience of pre-eclampsia was an important influencing factor. Barlow et al [38] in a study from UK found that two out of the 12 women interviewed had pre-eclampsia in previous pregnancies and as a consequence were aware of symptoms and signs in the index pregnancy, which led to them to self-refer for medical assessment and hospital admission by the process of early recognition and seeking professional help. The impact of having had pre-eclampsia in a previous pregnancy was also identified in the study in Brazil, however this knowledge resulted in a subsequent fear of the disease. The study did not specify if previous experiences and knowledge had altered women's help seeking behaviour [35]. The quote below from a woman who had had pre-eclampsia previously highlights the fear the women experienced;



*"I am afraid, I am afraid of having it again (pre-eclampsia)...it's because after the pregnancy I didn't have any high blood pressure problem, but then now on my second pregnancy I'm having it all over again (high blood pressure)..." ([35] p 184).*

**Subtheme 2: absence of or not recognising signs and symptoms** The synthesis identified that women's lack of knowledge may prevent them from seeking timely and appropriate medical support due to a lack of awareness of pre-eclampsia and its implications [34, 38–40]. However another finding includes women who did not notice the onset of symptoms and signs of pre-eclampsia which may have 'prompted' them to seek help. Barlow et al [38] found that seven of the 12 women in their study did not notice symptoms or signs at all and consequently felt 'frauds' when they were admitted as an in-patient and took up a hospital bed as the following quote illustrates.

*I was in shock and upset that I had to come in. The only thing I know is that I've got high blood pressure and protein and something in blood. It's to do with pre-eclampsia, but I didn't understand what this is cos I'm fine in myself and the baby's fine... and you're thinking why can't I go home? ([38] p161)*

Some women had difficulty differentiating between common pregnancy symptoms such as nausea, vomiting, heartburn, oedema and the early symptoms and signs of pre-eclampsia. Clinical staff also had similar problems [38, 41]. In two studies, women reported feeling that 'something wasn't right', with fatigue, not feeling well, shortness of breath, abdominal pain, nausea and vomiting, and severe right upper quadrant pain and reduced fetal movements all reported as symptoms and signs experienced by women questioned in the studies [38, 41]. The quote below was from a woman who experienced symptoms and signs of pre-eclampsia but did not seek help.

*"I had everyone in the world, who was wiser than me, telling me that this was heartburn, that this was reflux, that this was stomach problems, that this was tensions I actually let the pain go unchecked" ([41] p 48).*

**Subtheme 3: range of information needs** The studies selected for synthesis generated little insight into what information women needed, or when or how they would like to receive information. In four of the included

studies women would have liked more information on pre-eclampsia [31, 34, 36–38]. In the study from Jamaica, there was a marked decline in the incidence of eclampsia 6 months after women were offered information on what symptoms and signs to look out for, using pictorial cards, posters and antenatal education [34]. The authors' considered that the intervention resulted in an improvement in the women's awareness of the importance of action concerning particular symptoms and of response to clinical advice in general. It also had the unexpected benefit of providing a focus for discussion when the healthcare workers saw the women in the antenatal clinic. The study also appeared to have resulted in an increased awareness among the health care professionals of the prodromal symptoms of eclampsia reminding midwives of important symptoms and signs to look out for and treat [34].

Of note, is that not all women in this study were supportive of use of the pictorial card. Younger women in particular felt the card was not relevant to them they as it depicted an older woman [34].

Only one study reported that women searched the internet for more information regarding pre-eclampsia [39]. This was generally after women had a high risk screening test result for pre-eclampsia. Some of the women used the information to consider how pre-eclampsia would affect them and wanted to know how to prevent it from developing whereas others were more selective of the information.

One UK study which had conflicting results explored the psychological impact of providing women attending two maternity hospitals with risk screening information for pre-eclampsia in the first trimester of pregnancy, with conflicting results [39]. Although the majority of the women felt that if they knew they were at increased risk of pre-eclampsia they would have the advantage of being more likely to recognise the onset of the disorder; a minority questioned the usefulness of providing information for a condition that they perceived had no treatment and would increase their anxiety without providing a clear benefit [39]. These findings supported those of the earlier study by Harrison et al [40] in Canada who found that some women struggled to get the information they needed to participate in decision making. Other women were satisfied with passive involvement in decision making and wanted to trust the experts, perceiving healthcare professionals as having current and specialised knowledge that would be beneficial for them and their expected infant as the following quote illustrates.

*"If Dr M told me I had to stand on my head every morning for 10 min, I would do it. I would just do what she would tell me to do...they (doctors)\_ are a lot smarter than me." ([40] p112)*



The amount of knowledge required was affected by women's individual attitudes; an emerging finding was the impact of the women's emotions on help-seeking once they noted symptoms and signs of pre-eclampsia. This is discussed in the theme below.

**Theme 2: factors affecting help seeking behaviour from perspectives of women and their families'**

**Subtheme 1 emotions affecting help-seeking** Feelings and emotions were also found to alter women's help seeking behaviour and the amount of information they required. Fear was reported as affecting behaviour in five of the included studies [33, 35, 38, 39, 41]. Vasconcelos de Azevedo D et al. [35] found that women who were afraid of the disorder and were aware that they and their infants could be in danger as a consequence, knew they needed to seek urgent medical care. The women wanted to be listened to and needed to understand what was happening to them. Kidner [41] identified women experienced not only fear but also anger and women felt frustration during their efforts to seek relevant and timely information, as one woman explained.

*"I got frustrated with the physician. I was so frustrated I ended up crying at the doctor's office because I was full of frustration and not feeling very well" ([41] p 50).*

In Barlow et al's [38] study three women reported being anxious and scared; one woman had written a list of questions but was too upset to ask them. Another woman felt the doctors used big words or provided conflicting information as *"one says one thing and another says another"*. Here the perceived power imbalance between the health care professional who used complicated medical language affected the women's ability to secure an appropriate response for their concerns.

**Subtheme 2: social, cultural and economic disparities** Other factors that affected women's and their families help seeking behaviour reflected social and economic disparities as reported in the study from Bangladesh [32]. In the 'low performing' Sylhet district (this is a term used to describe a district which has low literacy levels and a high maternal mortality ratio compared to other districts), family members first administered treatment in the home even after convulsions had started and only when these attempts failed did they consider hospital admission. This was in contrast to a 'high performing' district, Jessore, where family members called in medical assistance and transferred the woman to a

health facility after the convulsing had started. Reasons proposed for these differences included cultural beliefs i.e. that eclampsia was associated with evil spirits and structural barriers i.e. not being able to locate transport to take the woman to a health facility [32]. One respondent in Sylhet said;

*"Dushi (evil spirit) turns on a pregnant women if she stays outdoors in the early morning, in the evening, and at noon, ignoring rules, and heavy bleeding occurs in this case" ([32] p 161).*

The study authors did not include quotes describing pre-eclampsia symptoms and signs but in three cases, the women's family members brought blessed water from a huzur (spiritual healer) as they believed that the Dushi was the reason for the convulsions.

Other sociocultural differences were also identified in the same study e.g. Sylhet women were less educated making them more reliant on relatives, more conservative with a fear of male service providers possibly attending them in a health facility and physical barriers including greater travel distances between the woman's home and the healthcare facility.

No other study specifically explored or compared impacts of social and economic disparities. In Canada, a woman's level of education was not associated with negotiation of participation in their health care decisions or with their level of satisfaction with their involvement in decision making [40]. It is possible the USA, UK, Brazil and Jamaica, had socioeconomic disparities which did affect help seeking, however it was not possible from the studies synthesised to identify differences in comparing women/health care professionals accounts from these perspectives.

**Subtheme 3; social networks influencing help-seeking** Three papers identified the influence of women's social networks on help-seeking behaviour [32, 38, 41]. Although positive emotional support was recognised [38], the potentially harmful influence of friends and family was also cited i.e. some women received false reassurance after seeking advice from other women regarding symptoms and signs [41]. This is reflected in the advice provided by a relative of a woman from Jessore who had developed a headache prior to fitting.

*"Everything was going fine...my daughter-in law told me that she was having headaches after lunch. I told her to lie in bed and to rest. Five minutes later when I came back to the room, I found that she was having convulsions, and her legs and head became curved. We did not wait much longer and took her to the hospital just after this." ([32] p165)*

### Theme 3: factors affecting staff response

**Subtheme 1: practitioner-client communications and relationships** There were limited findings on factors affecting healthcare professionals' responses to women and their families' presenting with self-diagnosed signs and symptoms of pre-eclampsia. Practitioner-client relationships were mentioned in some studies. In Brewer et al's [31] online patient questionnaire in the USA, open ended responses were collected from the question *"Is there any other information about this pregnancy that would be helpful to you?"* Improved provider communication was identified as one of the emergent themes from this question [31]. Desired areas for additional information included symptoms, definition of pre-eclampsia, improved provider communication, risk factors for pre-eclampsia, postpartum pre-eclampsia, closer monitoring, psychological support and complications and dietary concerns [31]. Vasconcelos de Azevedo [35] also identified a communication gap between women and health professionals with regard to their experiences of pre-eclampsia. For example, fear and risk were associated with the disorder for women, whereas for health care professionals their main focus was framed in terms of physical treatment.

Women were reported as finding the divergence of opinion about their symptoms and signs among health care professionals confusing and conflicting [38]. Barlow et al's [38] research highlighted the need for healthcare professionals to be consistent as crucial to enabling women's positive experiences of care. One woman noted that day and night shift professionals often provided inconsistent information. The quote below illustrates this issue:

*"I am fed up with it, cos they tell you different things... when I got brought in, they says you'll be in for a fortnight and you'll probably have the baby. And next breath....you'll probably have the baby in 2-3 days. Then everything is on a level, and they say, we want to keep you until 36 weeks now" ([38] p163).*

Again there was little to inform why inconsistent information was offered to women, but factors such as the model of care provision, the workload of wards or individual health care staff may have influenced the provision of information.

**Subtheme 2: Not being taken seriously** In three papers some of the women questioned reported symptoms and signs of pre-eclampsia but did not receive what they perceived to be an appropriate response from the healthcare professionals [34, 41]. An example of this was a young teenager who reported her symptoms to healthcare

professionals during attendance at a high risk pregnancy clinic, but was advised to take bed rest and return to the clinic after 1 week. She later developed eclampsia [34]. Nine women from the USA who had had HELLP syndrome with significant symptoms did not automatically seek medical assistance from healthcare providers. Some asked other older, perceived to be wiser, women about their symptoms, who reassured them that they were normal. Others had then escalated their concerns to health care professionals, but again were told not to worry as their symptoms were perceived as normal or resembled common pregnancy ailments, and advised not to worry [41]. After diagnosis the same symptoms and signs the women had reported were acknowledged as important and dangerous indicators of HELLP syndrome. This left women feeling betrayed after the preliminary delayed recognition and diagnosis. Additionally once admitted, some women felt their symptoms were devalued and treated as normal characteristics of pregnancy [41], as the following quote illustrates.

*"I spent most of the time between throwing up and arguing with the nurse. She was incredible! It was like something out of the movie or something. She was just standing there and hollering at me, saying things like, "You are not actually doing anything to help the pain go away, are you? I think you're bringing this on yourself. I have already seen how much Demerol they have given you and you shouldn't be in pain at all. There is no reason for it." I was just sickened and stopped talking all together." ([41] p48)*

Here the woman reported that the healthcare professional not only ignored her attempts to raise awareness of her symptoms, but belittled her, which had the effect of preventing the woman voicing her health care concerns again.

Although specific examples were not provided, Vanconcelos de Azevedo et al's [35] study highlighted that staff did not listen carefully to the women to understand how they were feeling and usually only considered their own perceptions.

Only one study investigated reasons why healthcare professionals did not respond appropriately to a woman seeking advice on regarding her symptoms. In MacGillivray's study, where a teenager was told to take bed rest and return again after 1 week, the doctor made his decision as the maternity ward was running over capacity [34].

### Discussion

Only 10 studies were eligible for inclusion in the narrative synthesis highlighting the limited amount of research available in this area. Furthermore in these



studies there was limited evidence of healthcare professionals' perspectives. Despite this, from the evidence considered in this synthesis, three main themes were identified; women's knowledge and understanding of pre-eclampsia and potential signs and symptoms of onset; factors affecting help seeking behaviour from the perspectives of women and their families' and factors affecting staff response. The most dominant theme related to women's lack of information and understanding of pre-eclampsia. Many wanted information on signs and symptoms, and experienced being offered conflicting information by healthcare professionals as disempowering. The synthesis also identified that some women did not develop noticeable "classic" symptoms or signs of pre-eclampsia or found it difficult to distinguish these from 'normal' pregnancy health. This is an important finding as it raises questions about the scope for women and families to contribute to this process given so many were unaware of signs and symptoms.

Many of the themes identified in the findings are supported by research in other health areas, for example that individuals need more information in order to become "the expert patient" [42], the belief being that by developing education programmes and creating expert patients, individuals are better able to take responsibility for their own self-management. However, expert patient research to date is often confined to individuals with chronic diseases such as diabetes [43]. There is little research exploring what are perceived as "normal" signs and symptoms of pregnancy and how best to differentiate between these and more serious symptoms and signs, which might indicate pre-eclampsia or eclampsia which is an acute medical emergency. Important finding was that only one paper linked socioeconomic disparities with help seeking behaviour [32] and pre-eclampsia. Other studies have identified the significance of literacy levels for help seeking [44]. The authors of a Belgian study suggested that those women at greater risk of severe pre-eclampsia were asylum seekers who did not receive adequate antenatal care as they were unfamiliar with the maternity system of the host country [45]. In the UK, the findings of a recent perinatal mortality report were that women from non-white ethnic groups and women in the most deprived quintile had stillbirth and neonatal death rates twice those of white women and those resident in the least socio-economically deprived areas (Maternal, Newborn and Infant Clinical Outcome Review Programme (MBRRACE-UK) 2016). The lack of findings in this narrative synthesis suggests this is an understudied area.

Another important finding is from the four studies that identified the influence of a family member or partner on a woman's help seeking behaviour [32, 34, 38, 41]. This ranged from generalised emotional support

[38] to women seeking help from other women regarding signs and symptoms [41] and receiving false reassurance, to women actually being prevented from getting urgent medical care needed [32]. The opposite was found in a qualitative organisational case study as part of the Birthplace in England research. Of 58 women interviewed regarding an escalation of care requirement, 14 reported speaking up in situations they felt to be urgent. The women also identified their relatives or support partners playing an important role in helping them to speak up [13] and illustrated how they can act as safety buffers by voicing concerns and pre-empting failures in care [13].

At times healthcare professionals had difficulties differentiating what women reported as important and requiring urgent escalation of care. Although the research was limited some women described not having their health care concerns responded to appropriately in some situations. Help seeking behaviour among the women could also have been affected by their attitudes and emotions [35, 39–41]. In some cases emotions such as fear for their safety and frustration encouraged women to speak up [35, 41], whereas in other cases emotions such as anxiety and being scared overwhelmed their ability to ask questions [38]. In [38] paper the perceived power imbalance between the health care professional and woman and the medical language used affected women's ability to secure an appropriate response to their concerns. The women's emotions were also affected by the health care workers behaviour supporting Nadler's [46] definition of help-seeking as "a three way interactive process that involves the recipient, the helper and the task or problem" [46]. Other studies also identified that women's attitudes and characteristics themselves affected whether or not they wanted to seek help [39, 40] for example if they wanted to be passive or active in their own care pathways. These studies did not indicate how differing behaviour patterns affected speaking up about signs and symptoms of pre-eclampsia, but possibly those women who relied on the expertise of staff would be less likely to question a health professional's decision to discount her concerns. These findings also challenge policy assumptions that all women want to actively contribute to their safety.

Thus the role of emotions when seeking help with symptoms and signs of pre-eclampsia cannot be isolated without understanding the complex sociocultural nature of help-seeking. Other authors have identified multiple variables of help-seeking with reference to symptom perception [47–51], but none have researched pregnant women and pre-eclampsia.

This systematic review and narrative synthesis has highlighted the paucity of research in this important area and raises a number of implications for future research.

Further research is needed to establish what information is needed, and how and when women and their families would most benefit from it. Understanding women's typologies; including those who want to be more involved in their care and those who want healthcare professionals to take responsibility, and how this affects their health seeking behaviour, warrants inquiry. This is an underexplored area and needs further investigation with respect to pre-eclampsia. A key finding of this review is that there is very little qualitative research available which explores how healthcare professionals' responses affect women's help-seeking with pre-eclampsia.

Implications for practice include health education to inform women and their families about symptoms and signs of pre-eclampsia/eclampsia, and raise awareness that some women may not develop noticeable signs and symptoms of pre-eclampsia or may find it difficult to distinguish these from 'normal' pregnancy characteristics. Healthcare professionals also need training and guidance on how and when to offer women information regarding pre-eclampsia and to be made aware that women's individual attitudes and emotional needs can affect help-seeking. Staff training also needs to address the importance of socio-cultural factors in women's self-monitoring, sense making of symptoms and signs and help seeking behaviours. Individual hospital guidelines and policies need to be developed accordingly, tailored to the needs of their local population. The new WHO antenatal guidelines recognised the importance of regular, high quality antenatal appointments which should include information on health promotion, and discussion of screening and diagnosis, and disease prevention [52].

#### Limitations of the syntheses

One of the limitations of this synthesis was the dearth of research in this area, which resulted in the inclusion of only 10 studies, which had a wide range of aims and methodologies. Mixed method papers were only included if they reported free text comments although it was often unclear how researchers had analysed the free text. For example You et al. [36, 37] stated that the patients' verbatim responses were recorded and independently rated as or correct or incorrect by their obstetrician. Women at different stages in their pregnancies were also included and the studies addressed a variety of research questions (some of which were quite different to the question asked for this synthesis) potentially shaping the nature of the findings. Capturing women's views retrospectively and contemporaneously, or narratives gained through repeat interviews over time may also have impacted negatively on the synthesis.

There was no demographic or geographic restriction to selected studies, which were carried out in a number of countries with different health care systems, sources

of funding and maternity care clinicians making it difficult to compare results. The study settings included upper, upper middle and lower income countries which also could have affected synthesis of the findings e.g. the ability of an individual to pay for healthcare is likely to impact on help seeking even when presenting with prodromal signs of pre-eclampsia. In addition transport and access issues will vary across the countries.

A further limitation is that any review will be subject to the research is available at the time and may be driven by the researcher's agenda rather than patient informed priority [53].

By analysing free text the aim was to capture the user and staff voice. However, by limiting the inclusion criteria to qualitative studies and mixed method studies with free text the scope of review may have been narrowed.

#### Conclusion

This narrative synthesis found a lack of knowledge and understanding about pre-eclampsia among women and their families, and a lack of awareness of the symptoms and signs of onset of the disorder. Of importance for healthcare professionals is the finding that not all women present with 'classic' symptoms and signs of pre-eclampsia or can distinguish these from normal pregnancy characteristics, with potential psychological, emotional and socio-cultural influences also likely to influence an individual woman's initial help-seeking behaviour.

Further research into women's information needs with regards to pre-eclampsia which stresses the importance of attendance at routine antenatal contacts, as well as raising awareness among healthcare professionals that their responses to women who do speak up can impact on women's help-seeking behaviours is needed.

#### Abbreviations

CQC: Care quality commission; ESRC: The UK economic and social research council; HELLPP: Haemolysis, elevated liver enzymes and low platelet; JLA: James Lind alliance; MBRRACE-UK: Maternal, newborn and infant clinical outcome review programme; NICE: National institute for health and care excellence; NPEU: National perinatal epidemiology unit; OSOP: One sheet of paper; PICO: Patient problem, intervention, comparison and outcome; RCM: Royal college of midwives; RCOG: Royal college of obstetricians and gynaecologist; SPICE: Setting, perspective, intervention, comparison, evaluation; UK: United Kingdom; USA: United States of America; WHO: World Health Organisation

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**Availability of data and materials**  
All data generated or analysed during this study are included in this published article.

WC was the main writer and substantially contributed to conception and design and analysis and interpretation of the data. WC, DB, NM, and JS were involved in revising the article critically for important intellectual content; for giving final approval of the version to be published. WC, DB, NM and JS participated sufficiently in the work to take public responsibility for appropriate portions of the content; and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. All authors read and approved the final manuscript.

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## **Appendix 2 Search Strategy for Narrative Synthesis**

A typical strategy for this search was: ("Pregnant women" or "pregnant women and their families" or patients or childbirth or midwi\* or obstetrician\* or hospital\* or manager\* or "maternity support worker\*" or childbirth or "health care worker\*" or labour or families or partners) AND (preeclampsia or "pregnancy complications" or "obstetric complications" or "pregnancy induced hypertension" or "high risk pregnancy" or eclampsia or "maternal mortality" or "maternal morbidity" or deterioration) AND ("patient participation in safety" or "patient collaboration" or "escalation of care" or "patient centred care" or "patient involvement" or "patient choice" or "nurse patient relations" or "doctor patient relations" or "patient empowerment" or "early warning systems" or signs or symptoms or "speaking up" or "seeking help" or "help seeking behaviour") AND ("women's experiences" or "staff response\*" or perception\* or attitude\* or behaviour\*).

Other methods included hand searching references lists and citation tracking.

## **Appendix 3 Women and family interview topic guidelines**

### **Women interviews**

#### **Questions for women using narrative analysis (25.06.15)**

**Research Title “Speaking up, Listening and Responding”; an exploration of factors affecting women with early warning symptoms of pre-eclampsia speaking up about the safety of their health in maternity care”**

*I am exploring women and their families’ stories to understand about their journey though the maternity services with the hope of contributing to improving services in the future. I am also going to be interviewing staff and charities.*

*Tell me in your own words the story of your pregnancy with any examples of how you became aware of pre-eclampsia and how it affected you and your baby. I may have some set questions at the end, but won’t interrupt you while you are telling me your story.*

#### **Set questions;**

1. How did you come to know there was a problem? How did you know it was pre-eclampsia?
2. Were you aware of any signs and symptoms of pre-eclampsia? If so, how did you feel about them and what did you choose to do?
3. Did you sense that pre-eclampsia posed a risk to you or your baby?
4. Did you feel the need to tell a health care worker or anyone else including your family about your or your baby’s health? If so, what prompted you to speak up about and to whom? What factors guided your decisions?
5. If you did speak up, how did health care workers respond to you regarding the health concerns you spoke about and what happened next?
6. If you chose not to speak to health care workers about this, can you share with me why not and what happened next?
7. How are you and your baby now and do you have an understanding of how having pre-eclampsia may affect your health in the future?



8. Can you think of any ideas that may have made your care easier regarding speaking up about signs and symptoms of pre-eclampsia.

## Appendix 4 Health care worker interview topic guidelines

### Questions for HCW (06.03.16)

*I am exploring health care workers stories to understand women's journeys through the maternity services with the hope of contributing to improving services in the future. I have also interviewed women and their families and will be interviewing charities.*

*Could you start off by recalling a recent situation where you were involved in managing a woman with suspected / actual preeclampsia – can you describe her presentation and care in detail?*

- *Was any diagnostic information missing or contradictory?*
- *Were there any factors that helped her diagnosis and management or contributed to delays / problems with managing care?*
- *What feelings did you have about this case and what influenced these feelings?*
- *If you felt positive about the management of this case can you recall and describe another where you felt less good? OR If you felt negative about the management of this case can you recall and describe an episode where you felt more positive about the management of a case?*

1. How and when do you make women aware of preeclampsia and of any signs and symptoms? (high risk women for low risk women)
2. Did you advise them of the risks of preeclampsia to themselves or the baby? (For high risk women for low risk women)
3. Did you ever have to give women a possible diagnosis of pre-eclampsia and how did you do this? (For high risk women for low risk women)
4. Any experiences of women themselves speaking up and self-referring re signs and symptoms of preeclampsia?

5. Timeliness for example in the obstetric assessment unit has been reported. What do you think about this? Are there ways to alleviate this?
6. Timeliness of waiting for bed to be clear in delivery suite before IOL. What do you think about this? Are there ways this can be relieved?
7. Pathways vary. Self-referral, ringing mw, GP routes are there ways of making women alert to different pathways
8. Post-delivery women traumatised as baby in SCBU and some women BP not settled. Reports of different Dr's giving conflicting medication advice. Are you aware of this and how can it be improved.
9. Discharge pathway and postnatal advice
10. BP machines, information leaflets, dipstick

## **Appendix 5 PPI interview template**

### **Questions for PPI using narrative analysis (21.09.16)**

**Research title “Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning symptoms of preeclampsia speaking up about the safety of their health in maternity care”**

*The aims of this study are to understand if women themselves can be an 'early warning system' regarding their health or their babies health; are they informed enough to raise concerns at an early stage, do they feel comfortable to speak up and do health professionals address their worries in an appropriate way.*

*I have interviewed staff, women and families in one NHS trust and I would like to interview you as a representative of.....to understand the experiences of members in your organisation which has much wider coverage.*

*Tell me a little about the role your organisation has in relation to women with preeclampsia? i.e. campaigning, reports, health professional training, helplines, fund research etc.*

#### **1. Theme signs and symptoms**

Do you get feedback on women's help seeking experiences when they have concerns?

What role do you consider the recognition of signs and symptoms play in this/or not?

Are there any strategies available to promote awareness of signs and symptoms of the onset of pre-eclampsia by your organisation?

What are these?

Do you know if they are helpful to women, and if so how?

Do you know how many women have accessed your information; how they use it, and how it has been helpful to them?

## **2. Speaking up affected by knowledge**

In your view, what is the best way to offer women and families' knowledge and information on signs and symptoms of pre-eclampsia without scaring them?

What is the best way to support healthcare staff to do this?

Many women and families are accessing information direct from internet. How is your organisation making information 'user' friendly and appropriate for different social and cultural groups?

How can women and families be made aware of different routes of access to information?

i.e. Different pathways for access for example phone calls, gp appointments, routine appointments, drop in clinics.

What are your views on women taking on more responsibility for self-monitoring their health such as taking their own blood pressure?

## **3. Speaking up affected by response form the organisation**

What are women telling you about their experience of maternity care and ongoing management after initial diagnosis?

What are women telling you about their experience of postnatal care and ongoing health needs and management particularly once they go home?

## **4. Emotional Impact**

What are the emotional affects that you hear about? Does your organisation offer emotional or other support during perinatal period?

## **5. Future improvements**

In your view what is done well at the moment and what needs to improve?

## **PROBES**

Education of women and families, verbal, posters or leaflets, education classes, group bookings, app with guidelines?

When is the best time?

How best to education staff on how to give information and how to communicate risk?

How can staff be made aware of changing guidelines? APP?

How can we deliver improved postnatal care for women with pre-eclampsia?

## **Appendix 6 Summary of stories**

**Woman 101, early twenties, Low risk at booking, diagnosed at 39 weeks in routine appointment. BP very high. 3+'s urine.**

W 101, was interviewed in her home. She was living in crowded accommodation with her boyfriend's parents. English second language was her second language. She arrived in UK in her midteens from Eastern Europe. She was very keen to give her story as had been diagnosed at 39 weeks in routine appointment, where her BP very high and there were 3+'s urine. She knew nothing about pre-eclampsia before this and was shocked about the diagnosis and sudden change in her perinatal pathway. When she was admitted she and her partner believed she would be induced immediately, but found themselves waiting on the ward for 4 days as there were no beds available on labour ward. She did have headaches on the ward and would call for help and felt appropriately responded to but became very stressed worrying about the baby on the ward. Her partner spoke up for her and the baby as to why they had to wait for four days. They both noticed women in "normal" labour going to labour ward and coming back with their babies. They were both distressed about this. On day four after admission she was induced, but had a long labour and finally an EMCS for fetal distress and failure to progress. Born at 40 weeks. After she was discharged back into the community nobody checked her blood pressure or advised her about the long term possible consequences of having pre-eclampsia. Both mother and father would have liked to know more about pre-eclampsia in early pregnancy and felt that women with normal pregnancies shouldn't have been prioritised over them.

**Short summary of W 105. Early 30's. Low risk at booking. At 32+ started having severe headaches 2 days before seeking help.**

W 105 was interviewed in SCBU. She was living with family member as husband abroad. She had severe headaches for 2 days and extreme tiredness and swelling. Partner had felt normal pregnancy signs and symptoms and advised her to rest. She rung the hospital and was advised to come in immediately. She knew nothing about

pre-eclampsia before this and was shocked at diagnosis. She was induced on admission and had a SVD at 32+. She was interviewed on SCBU where the baby was. On being given her diagnosis she googled and found out about pre-eclampsia and also contacted her friends. Since discharge no one had checked her blood pressure and she did not know about the long term consequences of pre-eclampsia. She felt that woman and their partners need to know about pre-eclampsia early in their pregnancies and felt by not knowing about it she was at risk in those first two days.

**W 106 30 to 35 year old. High Risk, Twins, 34+ Noticed signs and symptoms at home.**

W 106 was interviewed at home. She lived with her husband in a house they owned. She was high risk at booking with a twin pregnancy. She was informed about pre-eclampsia at booking and also researched it herself. She used this knowledge to help seek. At 34+ she noticed signs and symptoms at home. She was monitoring her own BP and protein in her urine. She noticed them rising. She had severe swelling, headaches and flashing lights. She saw, GP who said to go back in two days. She was confident and knowledgeable so rung hospital as felt this was not safe for her or the twins. The hospital said to come in ASAP. On arrival she had severe pre-eclampsia, clotting problems and an EMCS. The twins went to SCBU. Her BP did not stabilise for two weeks, and once at home she had to be very assertive to get home visit. She really valued monitoring own BP and urine and felt this would benefit all women help seeking and could be a differentiation between pre-eclampsia and eclampsia.

**W 122, High Risk at booking with essential hypertension. P2G2.**

W 122 was interviewed at home. She lived with her husband in council property. Drs asked W 122 to come into hospital as she had an missed appointment. On admission at 31 + she was found to have severe preeclampsia and had an immediate EMCS. Baby born 31+4 1300kg. Accepting of diagnosis. She said she did not know about pre-eclampsia and googled after diagnosis and read it was a "Silent Killer". This terrified her. She felt informed during care in hospital but felt there was "No post-



natal care". She felt people need to know importance of attending appointments as she had no signs and symptoms of pre-eclampsia even though she was very unwell.

## **Appendix 7 Research Protocol**



### **STUDY PROTOCOL**

Version 3: 25/03/2015

**Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning symptoms of preeclampsia speaking up about the safety of their health in maternity care.**

Title	<b>Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning symptoms of preeclampsia speaking up about the safety of their health in maternity care.</b>
Protocol Short Title/Acronym	<b>Speaking Up, Listening and Responding</b>
Protocol Version number and Date	Version 2: 18/03/15
Study Phase if not mentioned in title	Single Phase
Is the study a Pilot?	No
Study Hypothesis	N/A
Study Duration	3 years
Sponsor name	xxxxxx
Chief Investigator	Wendy Carter
REC number	
Medical condition or disease under focus	Pre-eclampsia
Purpose of study	To improve care management and experience of women and their families with pre-eclampsia
Primary objective	To understand the context and factors that affect women who experienced pre-eclampsia during or after the index pregnancy, their partners and families' ability to raise health concerns to healthcare professionals and for healthcare professionals to harness an appropriate response to facilitate optimal outcomes in the woman's and her infant's health
Secondary objective (s)	<p>1. To identify the range of health concerns (including early warning signs ) raised by women, their partners or families when women experience onset of severe pre-eclampsia during pregnancy, labour or the postnatal period.</p> <p>2. To identify the contextual factors that influence women, their partners and families decision making when raising concerns with health professionals about onset of severe pre-eclampsia.</p> <p>3. To identify the organisational and social factors that influence the health professional's ability to respond to health concerns raised by women and/or their partners/families regarding onset of severe pre-eclampsia.</p> <p>4. To identify what strategies (including information provided) are in place regarding pre-eclampsia that support women and their partners and families raising concerns and health professionals responding to them.</p>

Number of Subjects/Patients	40-50
Design	Qualitative Study
Main Inclusion Criteria	Organisational key stakeholders, health professionals, women who have had pre-eclampsia who are older than 16 years old. Partners or family member chosen by the women.
Methodology and Analysis	Thematic Analysis

Lead Sponsor

xxxx

& Co-Sponsor

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## TABLE OF CONTENTS



## **1.0 Lay Summary**

## **2.0 Background**

### **2.1 Defining safety and patient involvement with safety**

### **2.2 Current policy and support for patient safety initiatives**

#### **2.21 Acute health care settings**

#### **2.22 Promoting safety in the maternity services**

### **2.3 Strategies to promote patient and carer involvement with safety concerns**

### **2.4 Strategies to enable patients and carers to initiate a rapid response**

### **2.5 Factors that affect patients' involvement in patient safety**

## **2.6 Summary**

## **3.0 AIM**

### **3.1 Aims**

### **3.2 Objectives**

## **4.0 STUDY DESIGN**

### **4.1 Part 1: Key patient and public involvement interviews**

#### **4.1.1 Setting**

#### **4.1.2 Participants**

#### **4.1.3 Sample size**

#### **4.1.4 Data Collection**

### **4.2 Part 2: Women and family interviews**

#### **4.2.1 Setting**

#### **4.2.2 Participants**

#### **4.2.3 Sample size**

#### **4.2.4 Data Collection**

## **4.3 Part 3: Staff interviews**

### **4.3.1 Setting**

### **4.3.2 Participants**

### **4.3.3 Data Collection**

### **4.3.4 Data Analysis**

## **4.4 Patient Partnership**

## **5.0 Inclusion and exclusion criteria and diversity**

### **5.1 Inclusion criteria**

### **5.2 Exclusion criteria**

## **6.0 Diversity**

## **7.0 Research governance, Monitoring and Ethics and R&D Approval**

### **7.1 Informed Consent**

### **7.2 Confidentiality**

### **7.4 Potential Burden to patients**

### **7.5 Incentives**

### **7.6 R&D**

## **8.0 Finances**

## **9.0 Reporting and Dissemination**

## **10.0 References**

## **Glossary of Terms and Abbreviations**

AE	Adverse Event
AR	Adverse Reaction
APEC	Action on Pre-eclampsia
ASR	Annual Safety Report
CMACE	Centre for Maternal and Child Enquiries
CI	Chief Investigator
CRO	Contract Research Organisation
DMC	Data Monitoring Committee
EC	European Commission
FFT	Friends and Families Test
GAfREC	Governance Arrangements for NHS Research Ethics Committees
ICF	Informed Consent Form
IOC	Institute of Obstetrics and Gynaecology
Main REC	Main Research Ethics Committee
MNI-CORP	Newborn and Infant Clinical Outcome Review Programme
NHS R&D	National Health Service Research & Development
NICE	National Institute for Health and Care Excellence
NPSA	The National Patient Safety Agency
PI	Principle Investigator
PPI	Public and Patient Involvement
Participant	An individual who takes part in a clinical trial
REC	Research Ethics Committee
RCOG	Royal College of Obstetricians and Gynaecologist
Sands	Stillbirth and Neonatal Death Charity
SAE	Serious Adverse Event

WHO

World Health Organisation,

## 1. LAY SUMMARY

Pre-eclampsia is the most common of the serious complications of pregnancy, and remains a leading cause of maternal and perinatal mortality and morbidity. Pre-eclampsia is a serious pregnancy complication, which can affect any pregnancy. It can be dangerous to both mother and baby. Mild pre-eclampsia affects up to 10% of first time pregnancies with severe pre-eclampsia affecting about 1-2 in 100 severe pregnancies.

Pre-eclampsia involves changes in blood vessels all over the body. As a result: blood pressure rises protein from the blood leaks into the urine. Most women with pre-eclampsia are mildly affected, however some women become seriously ill with extra problems in the liver, brain, lungs or blood clotting system. Pre-eclampsia is a combination of hypertension and proteinuria and typically occurs after 20 weeks(National Institute for Health and Clinical Excellence 2011).

Early warning signs of severe pre-eclampsia, which can get worse very quickly, can be picked up first by women and families leading to earlier treatment. Specific symptoms include; severe headache that does not resolve with simple painkillers, problems with vision, such as blurring or flashing before the eyes, severe pain just below the ribs, heartburn that does not resolve with antacids, rapidly increasing swelling of the face, hands or feet and feeling very unwell (Royal College of Obstetricians and Gynaecologists 2012a).

If women or their partners and families are able to raise early warnings about potential signs and symptoms of pre-eclampsia in pregnancy, birth and in the postnatal period, they may be able to receive appropriate intervention to prevent severe pre-eclampsia from developing. Currently there is little evidence on whether women who have early warning signs of severe pre-eclampsia are able to raise their concerns, and get them taken seriously by health professionals.

This research will explore the potential of women and families to raise concerns about early warning signs of pre-eclampsia, and what affects an effective response from health care providers. An awareness of womens' ability to report

signs and symptoms of pre-eclampsia will also be explored from both women and health care providers' perspectives.

This research will focus on the factors that affect “speaking up” when women with a history of pre-eclampsia, their partners and families raise early warnings about potential complications in pregnancy, birth and in the postnatal period.

The approach will draw on interviews with key stakeholders, maternity service users and their families, and staff. The findings will be used to provide a basis for a future pilot study regarding an effective strategy for maternity service providers' and users' to communicate when an escalation of care is required.

## **2. BACKGROUND**

### **2.1 Defining safety and patient involvement with escalation of health concerns**

Patient safety with respect to prevention of serious health outcomes has been defined in two ways, one looking at the prevention of harm and the other looking more broadly at the components of quality care. An example of prevention of harm is “the avoidance, prevention and amelioration of adverse outcomes or injuries stemming from the process of healthcare”(Vincent 2010). Quality is defined in the “*Quality Chasm*” published by the Institute of Medicine (IOM) quality care as being; “safe, efficient, effective, equitable, patient-centred and timely” (Institute of Medicine 2001). This research will refer to both definitions.

Patient involvement in safety of healthcare is an emerging field, but it has been recognised in recent policies as a priority following a series of high profile health enquiries into NHS care as well as government–led health reviews and reports(Department of Health 2000) (Francis 2013)(Department of Health 2013a). It has also been highlighted by the World Health Organisation(WHO) who recognise that patients and carers are at the very centre of the quest to improve healthcare safety (World Health Organisation 2005). The Council of Europe and the World Alliance of Patient Safety have also recommended that

patients should be involved in reporting of incidents and safety management (World Health Organisation 2008)(Perneger 2008). WHO recognise that when there is a serious adverse event there can be an unwillingness to be open and honest about what happened, with patients not only the victims of the harm caused but also lacking ongoing counselling and support and an explanation of what went wrong with their care(World Health Organisation 2005).

Specific strategies in which patients can be involved in their own safety vary but can include amongst other things, providing important information about their medical history, observing and checking care processes, identifying and reporting treatment complications, and speaking up if they have any safety related concerns about the care they receive (Coulter & Ellins 2006). "Speaking up" is defined "as insistent and vehement communication when faced with failure by staff to listen and respond"(Rance et al. 2013). Patients in maternity and in general health care systems can experience unexpected deterioration in their physical and mental condition which can escalate to more serious consequences if they are not noticed and are untreated. Patients and their relatives may be aware of early signs of deterioration before staff or monitoring systems have identified any problems. Earlier detection and management may prevent serious problems developing.

One of the main causes of poor outcome to both mother and baby in pregnancy are hypertensive disorders which can lead to pre-eclampsia or eclampsia(National Institute for Health and Clinical Excellence 2011). Pre-eclampsia remains a leading cause of maternal and perinatal mortality and morbidity(Steegers et al. 2010). It is a pregnancy specific disease characterised by de-novo development of concurrent hypertension and proteinuria, sometimes progressing into a multisystem disorder (Steegers et al. 2010). It affects approximately 4-6% of pregnancies in the UK (Redman & Sargent 2005). The potential adverse perinatal outcomes include intrauterine growth restriction, preterm birth and fetal death (Tuuli et al. 2011).

Around 0.5% of women develop severe pre-eclampsia during pregnancy and can develop symptoms (Royal College of Obstetricians and Gynaecologists

2012a). Specific symptoms that the mother can be aware of for herself include; severe headache that does not resolve with simple painkillers, problems with vision, such as blurring or flashing before the eyes, severe pain just below the ribs, heartburn that does not resolve with antacids, rapidly increasing swelling of the face, hands or feet and feeling very unwell(Royal College of Obstetricians and Gynaecologists 2012a). There is little written about the signs and symptoms a woman can look out for in her unborn baby if she has pre-eclampsia. Women could be aware of slow growth(NHS Choices 2014) or reduced fetal movements. Although there are patient information leaflets for a woman to be aware of reduced fetal movements, these are not specifically for pre-eclampsia(Royal College of Obstetricians and Gynaecologists 2012b). The 2011 Centre for Maternal and Child Enquiry into maternal mortality identified that 20 out of 22 cases of maternal death from pre-eclampsia demonstrated substandard care and one factor was the failure to appreciate the significance of signs and symptoms and make appropriate referrals by health care professionals(Centre for Maternal and Child Enquiries 2011). The ability of women and their families to identify their own symptoms was not reported on. There is increasing evidence that individuals and their families in receipt of acute general health care or maternity care do not feel listened to even if they report concerns about signs and symptoms of ill-health, with the consequence that their health may deteriorate if appropriate care is not received(R. Francis 2013)(Care Quality Commission 2013)(Rance et al. 2013)(Redshaw et al. 2014)(Sands 2012).

There is limited research regarding women's involvement in their own safety with respect to adverse health outcomes in maternity. "Speaking up" was a problem recognised in the Birthplace Study (Rance et al. 2013) and NICE postnatal guidance recommended that women should be informed within 24hours of the birth of clinical signs and symptoms of potentially life threatening conditions (National Institute for Health and Care Excellence 2014). In acute general health care there is research that explores patient involvement with escalation of care (Gerdik et al. 2010a)(Greenhouse et al. 2006)(Luxford et al. 2011). These findings will be discussed in more detail in section 2.4.



## 2.2 Current policy and support for patient safety initiatives

### 2.21 Acute health care settings

As referred to above the importance of involving patients in their own safety has been recognised for several years. For example the report *An Organisation with a Memory*(Department of Health 2000) recommended that patients and their families should be involved about decisions in their care and that a mandatory reporting system for adverse health events and specified near misses should be established. This report led to the establishment of The National Patient Safety Agency (NPSA) in 2001 whose aim was to reduce risks to patients receiving NHS care and improve safety.

Patients' contribution to their own safety was at the core of "*Health Reform in England*" which outlined the need to develop a patient-led National Health Service (NHS) that used resources as effectively and fairly as possible to promote health, reduce health inequalities and deliver the best and safest healthcare(Department of Health 2006a). The Department of Health report "*Safety first*" recommended that patients and carers should be enabled to play an integral part in safety(Department of Health 2006b). In reality the campaign concentrated more on leadership and staff behavioural change(National Patient Safety Agency 2011) than involving patients in their own safety.

The Francis Report of the Mid Staffordshire NHS Foundation Trust Public Enquiry (Francis 2013) identified that "*appalling suffering of many patients*" was primarily caused by a serious failure of a provider Trust Board to listen sufficiently to its patients and staff or ensure the correction of deficiencies brought to the Trust's attention(Francis 2013). Since this report there have been a strategies and reports to improve patient safety. These include the Berwick Report, the Keogh Review, the "Sign up to Safety" campaign and the publication of two volumes of "Hard Truths: the journey to putting patients first(Department of Health 2014)(Keogh 2013)(National Advisory Group on the safety of patients in England 2013) (National Health Service England 2014)(The

National Health Service 2014a) and the “Friends and Family Test”(FFT)(The National Health Service 2014b).

The Berwick report published in 2013 highlighted the importance of the patient’s voice most effectively. It recommended that *“patients and their carers should be present, powerful and involved at all levels of healthcare organisations from ward to the boards of Trusts”*(National Advisory Group on the safety of patients in England 2013). The report acknowledged that *“involvement means having the patients voice heard at every level of the service, even when that voice is a whisper”*(National Advisory Group on the safety of patients in England 2013). The Health and Social Care Act (2012) also emphasised the importance of putting the patient first by providing details of how to increase the patient voice e.g. regarding patients there was to be *“no decision about me without me”*(Department of Health 2012).

In practice there are few strategies directly for patients to have their voice heard regarding their own safety with the exception of the FFT. It is currently being used as a feedback tool in the NHS for both patients and staff with the aim of allowing patients and staff the chance to raise concerns about standards of care(NHS England 2013). Patients are encouraged to fill in a survey as to whether they would recommend the hospital to a friend(NHS England 2013). In maternity the women are given the survey to complete by staff during four stages of care, antenatal, intrapartum, on the postnatal wards and in the community postnatally(NHS England 2013). The preliminary results published on NHS choices are available but have limited value due to the low response rate and inconsistent system for gathering feedback(Bibby 2013).

## **2.22 Promoting safety in the maternity services**

Research is limited regarding women’s involvement with promoting their own safety when in receipt of maternity care, however previously published enquiries such as the triennial Confidential Enquiry into Maternal and Child Health (CEMACH) identified similar findings to the Francis Enquiries and the Berwick Report with respect to organisational failures (CMACE 2011). The confidential

enquiries into maternal deaths have been held since 1952 to assess the main causes of maternal deaths and through identification of avoidable causes, to reduce maternal morbidity and mortality by recommending improvements in clinical and service provision (Weindling 2003). Over the years the findings have identified a range of issues impacting on maternal outcomes including; clinical failure to identify severity of illness and consequent provision of suboptimal treatment; staff with inadequate clinical experiences and or skills; leadership and management issues; delayed or inappropriate decision making; lack of consultant involvement; equipment problems; poor team work; inadequate support services i.e. interpreters and particular to maternity problems with fetal surveillance (National Patient Safety Agency 2007c) (Lewis G (ed) 2001).

To improve safety the 'Saving Mother's Lives' (2007) report listed 10 recommendations which were designed to be audited, one of these was to use early warning systems to assist in the detection of deteriorating health (Confidential Enquiry into Maternal and Child Health 2007). The report highlighted that socially excluded women are at higher risk of death during or after pregnancy than other women. The perinatal mortality report also identified this and showed that women from non-white ethnic groups and women in the most deprived quintile had stillbirth and neonatal death rates that were twice those of white women and those resident in least deprived areas (Confidential Enquiry into Maternal and Child Health 2009). The NICE guideline for pregnancy and complex social factors identified 4 vulnerable groups; women who are particularly at risk are those women who misuse substances, young women under 20, refugees, asylum seekers and women who do not speak English and women who experience domestic violence (National Institute for Health and Care Excellence 2010).

The eighth report showed an overall fall in maternal deaths in the UK but a rise in the number of women dying from sepsis and women who had comorbidities, such as older women and women with a higher Body Mass Index, have higher maternal and infant morbidities during the perinatal journey (Centre for Maternal and Child Enquiries (CMACE) 2011). Interestingly the Enquiry showed a

reduction in the inequalities gap (Centre for Maternal and Child Enquiries (CMACE) 2011). This was the last report and has been replaced by a Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP)(Kurinczuk et al. 2014).

More recent reports regarding safety in the maternity services explored the patient experience for example “*Maternity services in England*” and the recent “*Care Quality Commission Survey*” (Department of Health 2013a)(Care Quality Commission 2013). Although not investigating service users involved in their own safety, the “*Maternity Services in England*” analysed women’s experiences of their care in two maternity services surveys, one conducted in 2007 by the Health Care Commission and the other in 2010 by the Care Quality Commission(Department of Health 2013a). The 2010 survey found that 80% of women reported excellent care during labour and birth, which declined to 67% for care after the birth. There was a significant difference in the level of satisfaction reported between white women and women from black and other minority ethnic groups (Department of Health 2013a) i.e. 75% of black and ethnic mothers rated care during labour and birth as very good or excellent, compared with 86% of white mothers and the black and ethnic mothers were more likely to report shortfalls in choice and continuity of care(Department of Health 2013a).

A recent Care Quality Commission Survey (2013) reflected different patient experience results from the “*Maternity Services in England Report*” and highlighted the wider public health concerns of not being listened to. It showed that out of 23,000 women surveyed, 19% felt their concerns during birth and labour were not taken seriously(Care Quality Commission 2013).

In acute general health care and in maternity care there is growing evidence that patients and their families do not feel listened to if they have concerns about their health. As a consequence their health may deteriorate if an appropriate response from healthcare professionals is not initiated(R. Francis 2013)(Care Quality Commission 2013)(Rance et al. 2013)(Redshaw et al. 2014). This was also an unexpected finding in the qualitative organisational

case study part of the Birthplace in England review (Rance et al. 2013). Of 58 women interviewed 14 reported speaking up in situations they felt urgent. Examples of safety alerts included requests for attendance in labour, signs of risk in labour and neonatal pathologies. The women also identified their relatives or support partners playing an important role in helping them to speak up (Rance et al, 2013). This research also highlighted that “speaking up” was no guarantee of being listened to, or having an appropriate response from a healthcare professional. Examples of staff failure to listen and respond included ignoring requests or dismissing safety alerts; delaying or withholding information, care or support; disbelieving the woman’s account, responding brusquely, refusing labouring women admission or sending them home feeling unsafe; refusing the presence of midwife to attend a planned homebirth(Rance et al. 2013).

Another finding of the *“Maternity Services in England Report”* was a high mortality rate for babies in 2011, 1/133 babies were stillborn or died within seven days of birth(Department of Health 2013a). Five main causes of stillbirth have been identified; childbirth complications; maternal infections in pregnancy; maternal medical disorders; fetal growth restriction; and congenital abnormalities(Lawn & Kinney 2011). Stillbirth rates are also increased for those living in social deprivation, women who are obese, those who smoke, and older women(Flenady et al. 2011). The Lancet Series on Stillbirth presented strategies to reduce stillbirth rates which included improvement of health and well-being of women before, during and after pregnancy: detection and management of women at risk during pregnancy and improvement of information and standards of maternity care (Bhutta et al. 2011). However, the UK has one of the highest rates of stillbirth at 3.8 stillbirths per 1000 births of 12 high income countries and these rates have remained static compared to other European countries, for example Norway and the Netherlands, which have succeeded in reducing their rates (Flenady et al. 2011). One of the ways Norway reduced its stillbirth rate by half was by following an educational programme encouraging women to report a change in fetal movements promptly and receive an appropriate care pathway (Tveit et al. 2009). This could

be seen as a successful strategy of patient involvement in their own safety to reduce the stillbirth rate in Norway.

Although the reasons for high stillbirth rates are complex and need further exploration there is a possibility in the UK that families' voices are not heard during either the antenatal, birth or postpartum period e.g. when speaking up about a change in the normal pattern of fetal movements. The most recent Stillbirth and Neonatal Death Charity (Sands) report cited that of the women whose baby died before labour only 57% felt listened to or their concerns taken seriously and of the women whose baby died during labour a quarter felt that staff communicated poorly, almost half did not feel listened to and around 10% reported rarely or never having trust or confidence in the staff caring for them during labour and birth (Redshaw et al. 2014). The most common finding for women and partners whose baby died before labour was that 72% recognised that something was wrong with changes in their babies normal pattern of movement (Redshaw et al. 2014). When they were asked about raising their concerns to health care professionals a third of women reported contacting a clinician straight away and 46% within 24 hours, only 57% felt listened to at this time and 39% were confident of decisions made (Redshaw et al. 2014). This is significant as a significant reduction or sudden alteration or absent fetal movements may be an warning sign of fetal death (Royal College of Obstetricians and Gynaecologists 2011). Interestingly the NICE antenatal guidelines do not recommend routine fetal movement checking by women (National Institute for Health and Clinical Excellence 2010a), whereas the Royal College of Obstetricians and Gynaecologist recommend that "*women should be aware of fetal movements up to the onset of labour and should report any cessation or decrease in movements to their maternity unit*" (Royal College of Obstetricians and Gynaecologists 2011). This confusing professional advice could be why user groups and charities are taking their own action, for example Sands is funding a large study AFFIRM, which is looking at the way maternity units respond to women with reduced fetal movements in 36 units in the British Isles (Stillbirth and Neonatal Death Charity 2014) and the MAMA academy has a website where the public are able to download their own "daily movements checker" specifically to alert women about the risks of reduced fetal

movements and to give them the confidence to ask for help(MAMA Academy 2014). These findings could be relevant to pre-eclampsia as in the most recent UK perinatal mortality report, 5% of stillbirths in infants without congenital abnormalities occurred in women with pre-eclampsia and half of women with pre-eclampsia gave birth preterm (National Institute for Health and Clinical Excellence 2011). In addition small for gestational babies were common with 20-25% of preterm birth and 14-19% of term birth in women with pre-eclampsia being less than the tenth centile of birth weight for gestation (National Institute for Health and Clinical Excellence 2011). It is possible that reduced fetal movements could be one of the signs women could look out for due to the high incidence of small for gestational age babies whose mothers have had pre-eclampsia. Currently women are not advised that this could be one of the symptoms for their babies in either the RCOG guidelines or the NHS Choices guidelines (Royal College of Obstetricians and Gynaecologists 2011)(NHS Choices 2014) .

Currently there are a limited number of strategies for service users to initiate a rapid response to a sudden deterioration in health. Strategies and factors that can affect patients and carers being involved in their own safety are discussed below.

### **2.3 Strategies to promote patient and carer involvement with safety concerns**

In reality there may be many barriers and facilitators to patients being involved with their own safety. A few examples of these will be briefly described before exploring patient involvement in their own care when there is a deterioration in their health. Patients' attitudes towards engaging in error prevention and the effectiveness of efforts to increase patient participation in safety were explored in a systematic review which identified 21 studies in the inclusion criteria (Schwappach 2010). These studies included patient involvement in challenging staff to wash their hands (Duncan 2007)(Duncanson & Pearson 2005)(Luszczynska & Gunson 2007), patients being involved with preventing medication errors(McGuckin et al. 2001)(Weingart et al. 2004), patient

involvement with prevention of surgical errors (DiGiovanni et al. 2003) and more general research into patient involvement with safety (Entwistle et al. 2005). Amongst other findings the evidence suggested that patient involvement in safety may be successful if interventions promote complex behavioural change (Schwappach 2010). This systematic review did not identify any research regarding patients contributing to their own safety in maternity or when their health is deteriorating suggesting more research may be needed in this area.

A systematic review by Hall et al (2010) regarding the effectiveness of interventions designed to promote patient safety identified 14 individual experimental and quasi-experimental studies and one systematic review. They found that the majority of the studies were related to enhancing medication safety and concluded that there was limited evidence for the effectiveness of interventions designed to promote patient involvement in patient safety incidents (Hall et al. 2010). However a more recent systematic review examined how patients and families could reduce adverse events in acute care settings (Berger et al. 2013). The review identified 12 prospective controlled design studies in hospital settings that addressed the effectiveness of implementation of patient/family engagement in patient safety practice. A wider range of interventions were identified such as hand washing (McGuckin et al. 2001)(McGuckin et al. 2011), patient engagement in prevention of healthcare associated infection(Hart 2012), patient engagement of surgical checklist interventions(Garnerin et al. 2008)(Nilsson et al. 2010), patient engagement in falls interventions(Krauss et al. 2008)(van Gaal et al. 2011), patient involvement in transitional care(Coleman et al. 2004)(Parry et al. 2009)(Voss et al. 2011), it also included patients involvement in rapid response strategies (Gerdik et al. 2010a). This will be explored in more detail below.

## **2.4 Strategies to enable patients and carers to initiate a rapid response**

Strategies that utilise patients' and their relatives' awareness of early signs of health deterioration before staff or monitoring systems have picked up any problems include a rapid response strategy which was piloted and then implemented on a wider scale in Jacksonville Medical Centre, USA (Gerdik et



al. 2010b). This was for patients and their families in an adult level 1 trauma unit. An education programme and phone number was given to patients to alert the medical team if they felt their health was deteriorating and they were unable to solicit an appropriate response. A two year review of the data indicated that morbidity improved (Gerdik et al. 2010a).

There are other strategies in acute general health care in the USA, Australia and UK (Greenhouse et al. 2006) (Luxford & Lee 2013) (Odell et al. 2010a). At the University of Pittsburgh's Medical Centre, a paediatric rapid response strategy, a hotline was given to patients and their families to ring if they had concerns about the patient's condition and they were unable to find immediate clinical support. This was called Condition H(elp) System. This activated a multi-disciplinary response team to assess and manage the situation (Greenhouse et al. 2006). A 9 month pilot study showed positive results of improved patient and family satisfaction and the programme helped to stabilise patients who were at risk of a health deterioration (Greenhouse et al. 2006). The programme was rolled out in 14 other hospital sites. This project inspired a recent small feasibility study in an 800 bed district hospital in the UK, "Call 4 Concern" (C4C). A phone number was given to patients and relatives to activate critical care outreach following transfer from the intensive care unit to the main ward. It had positive results and showed that it had the potential to prevent clinical deterioration and improve patients experience, however the study had a very small sample size (Odell et al. 2010b). Other examples of similar projects include "Speak Up" in the USA (The Joint Commission 2002), "Please Ask" in the UK (National Patient Safety Agency 2010), and in Australia the REACH toolkit (Luxford & Lee 2013). There has been little published data on the effectiveness of the latter tools and none included maternity care.

There are limited strategies in maternity to enable women and their carers to initiate an escalation response. With respect to pre-eclampsia there are information leaflets for women regarding signs and symptoms and the importance of seeking medical help has been included in publications by the Royal College of Obstetricians and Gynaecologist and NHS Choices (Royal College of Obstetricians and Gynaecologists 2012a) (NHS Choices 2014). NICE

guidance on hypertension in pregnancy recommended that women should be made aware of the need to seek immediate advice from a health care professional if they experience symptoms of pre-eclampsia (National Institute for Health and Clinical Excellence 2011), but there is no indication of when this should occur and who the women should contact, and if this is occurring in practice. This is also the case for the NICE postnatal care guidelines, where women should be offered information within 24 hours after the birth of potentially life-threatening conditions both to themselves and their babies as described earlier. (National Institute for Health and Care Excellence 2014). A recent report that looked at implementation of the NICE quality standards on postnatal care found that 47% of mothers were not made aware of signs of health deterioration in the postnatal period, despite the recommendations (The Royal College of Midwives 2014). Only 23.5% were made aware about the signs and symptoms and 29.5% could not remember if they were told about the symptoms or not (The Royal College of Midwives 2014).

Despite these national guidelines much of the advice available for women regarding signs and symptoms of potentially adverse health outcomes have been developed by charitable organisations e.g. Sands and Mama Academy regarding fetal movements and Action of Pre –Eclampsia (APEC) regarding the signs and symptoms of pre-eclampsia (Action on Pre-eclampsia 2014). The variation in guidance of what women should be made aware of regarding signs and symptoms of health deterioration during and after pregnancy could impact on their ability to speak up.

A new Maternity Safety Thermometer Survey is to be commenced at the end of November 2014 following a pilot phase from June 2013 to October 2014. This is a voluntary online survey where organisations can measure harm in maternity. Areas surveyed will include perineal and or abdominal trauma, post-partum haemorrhage, infection, separation from baby and psychological safety (NHS Safety Thermometer 2014). Interestingly one of the questions that will be asked to the women will be if they raised safety concerns during labour and birth and if they felt they were taken seriously.

## **2.5 Factors that affect patients' involvement in their own safety**

Although current health policies advocate patient involvement in their own safety there may be many factors which affect how easy this is for patients and their families.

Perhaps the most important factor of involving patients in their own safety is their willingness and ability to “speak up”. This was explored in a systematic review by Doherty et al (2012) which included 68 studies that either investigated initiatives that involved patients in safety or their perspectives of being involved in safety initiatives. The findings showed that the main factors that influence patients ability to be involved in their own safety were illness, individual cognitive characteristics, the clinician–patient relationship and organisational factors(Doherty & Stavropoulou 2012). They concluded that patients fear of being labelled difficult and a consequent desire for clinicians approbation may cause them to assume a passive roles as a means of actively protecting their personal safety(Doherty & Stavropoulou 2012). These findings are not isolated. An earlier literature review identified five factors that influenced patient involvement with safety which were: patient related( e.g. patients demographic characteristics), illness related (e.g. illness severity), health professional-related (e.g. health professionals' knowledge and beliefs), health care setting (e.g. primary or secondary care), and task related (e.g. whether the patient safety behaviour challenges clinician clinical abilities)(Davis et al. 2007). The authors concluded that although patients could act as safety buffers during their care the responsibility for their safety must remain with the health professional with further research needed to examine influences and impact of patient involvement in safety(Davis et al. 2007). In a more recent study, Rance et al (2013) also found that women “speaking up” in maternity was not enough and that organisation-focused efforts were also required to improve staff response(Rance et al. 2013).

## **2.6Summary**

Current government policy supports the need for patients and families to participate in their own safety when receiving care, however there is limited research available regarding patients involved in safety initiatives and very little in maternity.

This study will explore the potential of maternity service users and families to raise signs and symptoms of pre-eclampsia and harness an appropriate response from health care providers to contribute to optimal maternal and infant health outcomes.

This study could be an important resource to understand current social and organisational factors that affect women and their families speaking up and how health professionals can be facilitated to listen and respond appropriately so that improvements can be made in the future. The empirical research will be qualitative as these studies are able to understand more about a phenomenon rather than to measure it (Green & Thorogood 2009).

The findings will be used to provide a basis for a future post-doctoral pilot study regarding an effective strategy for maternity service providers and users' to communicate when an escalation of care is required.

### **3. AIM**

#### **3.1 Aims**

To understand the context and factors that affect women who experience early warning signs of severe pre-eclampsia during or after the index pregnancy, their partners and families' ability to raise health concerns to healthcare professionals and for healthcare professionals to harness an appropriate response to facilitate optimal outcomes in the woman's and her infant's health.

#### **3.2 Objectives**

1. To identify the range of health concerns raised by women, their partners or families when women experience onset of pre-eclampsia during pregnancy, labour or the postnatal period.
2. To identify the contextual factors that influence women, their partners and families decision making when raising concerns with health professionals about onset of pre-eclampsia.
3. To identify the organisational and social factors that influence the health professional's ability to respond to health concerns raised by women and/or their partners/families regarding onset of pre-eclampsia.
4. To identify what strategies (including information provided) are in place regarding pre-eclampsia that support women and their partners and families raising concerns and health professionals responding to them.

#### **4. STUDY DESIGN**

This research project will use semi-structured interviews, with three complementary elements; (1) a qualitative exploration of patient and public involvement group representatives' perceptions and experiences of "speaking up" about maternal health needs, (2) a qualitative exploration of maternity service users and their families' perceptions and experiences of "speaking up", and (3) a qualitative exploration of staff perceptions and experiences of listening and responding to maternity service users and their families' when "speaking up" .

##### **4.1 Part 1: Patient and public involvement interviews**

This will be a qualitative exploration of patient and public involvement user groups' perceptions and experiences of the women, their partners and families that they represent. This will include charities, advocacy organisations and user groups. The interviews will generate an in-depth knowledge from each organisation of safety concerns raised by women, their partners and families

regarding pre-eclampsia when there is a deterioration in health or escalation of care. The information will be used to inform topic guides for interviews with the women and their families.

#### **4.1.1 Setting**

Interviews will be conducted at a place and time convenient for the participant. This could include their home or a private room in the community or hospital setting. A telephone interview will be offered if this is preferable.

#### **4.1.2 Participants**

A purposive sample strategy will be used to capture the perceptions and experiences of key PPI representative from each group. This is where respondents are selected that are most likely to yield appropriate and useful information (Bourgeault et al. 2013). The sample will include coordinators or managers of patient participation groups and charity groups who have connections to women and families who have experienced pre-eclampsia such as Tommy's, Action on Pre-eclampsia (APEC), Maternity Service Liaison Committees (MSLC), National Childbirth Trust (NCT), Stillbirth and Neonatal Death Charity (Sands).

One participant from each of these PPI groups will be interviewed as these organisations are involved with designing and researching services and also represent the voices of maternity service users and staff. The organisations represent a wide range of maternity service users and it is expected that expert knowledge of social and medical complexities regarding pre-eclampsia will be provided. This may give an understanding of the scale and nature of the problem and the factors that influence it.

#### **4.1.3 Sample size**

The estimated sample size is 5 as it is believed that this will provide a wide range of perspectives to inform the study. If important themes and differences

are found within these interviews, sample size may be expanded to reach theoretical saturation (Bourgeault et al. 2013).

#### **4.1.4 Data collection**

The interview schedule will be developed from the literature review and feedback from patient partnership (see 4.4). Topic guides will be used, with the researcher using open ended questions exploring stakeholder's perceptions of the scale and the nature of the problem and the factors that influence it. Data will be collected through one to one semi-structured interviews lasting for approximately one hour.

Recruitment of PPI participants will be achieved through an email invitation sent by the researcher. Prior to the interviews informed consent will be obtained for interviewing, recording, transcribing and possible publication of the findings. To ensure confidentiality no data will include identifiable information. Audio recordings will be transcribed using pseudonyms or code names to protect the confidentiality of participants.

The interviews will take place at a site chosen by the interviewee either in a hospital, work, home or neutral setting. Phone interviews will be offered if that is the preferred option of the participant.

### **4.2 Part 2 Women, partner and family interviews**

The aim of Part 2 is to identify the signs and symptoms of onset of pre-eclampsia raised by women, their partners and families and the factors that influence them being raised and responded to. The findings will be used to influence the topic guides for the staff semi-structured interviews.

#### **4.2.1 Setting**

Similar to part one interviews will be conducted at a place and time convenient for the participant. This could include their home or a private room in the community or hospital setting. A telephone interview will be offered if this is preferable.



#### **4.2.2 Participants**

Women of all parities who have had pre-eclampsia and their families will be selected from different socio economic backgrounds, ages, and ethnicities as women from a range of socio economic backgrounds and ethnicities have different maternal outcomes despite universal healthcare (Confidential Enquiry into Maternal and Child Health 2007).

By selecting a range of women and their families from these different categories it is hoped there will be a range of experiences and perceptions identified.

#### **4.2.3 Sample size**

Purposive heterogeneity sampling will be used to select approximately 20 women and their partners or family members, as chosen by the women. This method has been chosen as it can lead to a greater depth of information from carefully selected cases (Teddlie & Tashakkori 2009).

#### **4.2.4 Data Collection**

As above data will be collected by one to one semi-structured interviews lasting approximately one hour.

Women who have been identified with an episode of pre-eclampsia as defined by women who develop a new hypertension presenting after 20 weeks with significant proteinuria (National Institute for Health and Clinical Excellence 2011) will be identified by case note records by research midwives and approached by on either on the postnatal ward or in postnatal community clinics. They will be informed about the study and offered an information leaflet. If they are interested the midwives will ask if they can give the women's mobile phone numbers to the researcher to contact them to provide more information.

If interest is shown a date for a potential interview and venue would be chosen by the women. On the chosen day a further information sheet was given and

read by the researcher to the participants. A consent form will then filled in and signed by the participant for the research to take place and the same protocol will be followed as stated above.

The interviews will take place up to 3 months after the birth of the baby in order for the women to discuss their whole journey through pregnancy, the birth and the postnatal period.

#### **4.2.5 Data analysis**

Primary data from the semi- structured interviews will stored and managed using Nvivo software. Data will be analysed using a thematic analysis approach. The transcripts will be analysed and compared to enable recurrent themes to be categorised (Green & Thorogood 2009). To strengthen interpretative rigour, supervisors will be consulted during the primary data analysis and findings will be shared with a wide reference group including public and patients. Respondents will be asked to clarify issues or events if needed.

#### **4.3 Part 3: Staff interviews**

The aim of this phase is to identify the organisational and social factors that influence the health care provider's ability to respond to health concerns raised by women concerned about their health symptoms and to identify the role of strategies and practices in enabling both women to raise concerns and healthcare professionals to respond to them.

##### **4.3.1 Setting**

Findings from the interviews in Part 1 and 2 will inform the interview topic guide for staff.

Private rooms will be booked for staff interviews in the hospital setting. Phone interviews will be offered if requested.

#### **4.3.2 Participants**

Purposive heterogeneity sampling will be used for the interviews of staff. Approximately 8 midwives, 3 obstetricians, 2 care assistants/administration staff, and 2 managers will be selected. Midwives representing Bands 6, 7 and 8 and obstetricians will be selected.

#### **4.3.3 Data collection**

Recruitment of staff participants will be through email invitation of the researcher. Interviews of staff participants will take approximately one hour. The interviews will be conducted in private hospital rooms booked in advance.

#### **4.3.4 Data analysis**

Primary data from the semi- structured interviews will stored and managed using Nvivo software. Data will be analysed using a thematic analysis approach. The transcripts will be analysed and compared to enable recurrent themes to be categorised (Green & Thorogood 2009). To strengthen interpretative rigour, supervisors will be consulted during the primary data analysis and findings will be shared with a wide reference group including public and patients. Respondents will be asked to clarify issues or events if needed.

#### **4.4 Patient Partnership**

Maternity service users have been involved in the design of the study, helped to develop the study questions and contributed to discussions about the study methodology. This was achieved by presenting early stages of the research protocol at meetings of the Maternity Services Liaison Committee, National Childbirth Trust and Pre-term Birth Studies Panel. The plan is to continue patient partnership involvement at both the primary data analysis stage and before and during dissemination of the final report.

### **5.0 INCLUSION AND EXCLUSION CRITERIA**

#### **5.1Inclusion criteria**

1. Organisational key stakeholders, women who experienced pre-eclampsia in the index pregnancy over 16 years old and their partners/families.
2. As partners or family member will be chosen by the women as the person who is significant to them, women will not be excluded who do not have a partner or family member, or if their partner/family do not wish to participate in the study.

## **5.2 Exclusion criteria**

1. Women under 16.

## **6.0 Diversity**

The host NHS trust is in inner city area with a diverse population, socio economically, culturally and ethnically. This will provide a potentially diverse sample of women, partners and families. For those women and partners who do not speak English as a first language, resources for translation have been identified in the study budget either by using language line or translators. Posters for the organisational observations will be printed in several languages which are most prevalent at the host site.

## **7.0 Research Governance, Monitoring and Ethics and R&D Approval**

### **7.1 Informed Consent**

Information leaflets about the project will be distributed in clinical areas such as antenatal clinics, postnatal wards and community clinics. The researcher will explain her role and answer questions as frequently as possible. Research interviews will take place either in the health facility or home depending on the choice of the participant. Staff interviews will be in the hospital setting in private rooms. Prior to the interviews informed consent will be obtained for interviewing, recording, transcribing and possible publication of the findings. Participants will be made aware that they can withdraw consent for specific aspects e.g. recording/transcribing. Safety of the researcher will also be taken into account following Social Research Ethical Guidelines practices will be followed (National Health Service 2009).

### **7.2 Confidentiality**

The study will comply with the “Data Protection Act”(Crown Copyright 1998) and the Department of Health “Code of Practice for Confidentiality”(Department of Health 2003). Manual files such as tapes and paper documents will be stored securely in a locked filing cabinet at Kings’ College London. No data will include patient identifiable information. Audio recordings will be transcribed using pseudonyms or code names to protect the confidentiality of participants. When the results are published the pseudonyms will be used. Computer records will be password protected. Sources of data will be kept according to Kings’ College local policy on research data for 25 years complying with the Congenital Disabilities(Civil Liability) Act(1976).

There may be clinical safety concerns raised in the interviews. The researcher will immediately escalate the concern to a senior member of the clinical team and her supervision team. This follows the Nursing and Midwifery Council guidance which states “*as a nurse or midwife, you have a professional duty to put the interest of the people in your care first and to act to protect them if you consider them at risk*”(Nursing and Midwifery Council 2013). If systemic threats to the patient are reported or a patient or relative raises a concern, but these do not constitute an immediate threat to the patient these will be reported to the supervision team.

Participants will be warned that, should any malpractice be revealed during the research, the researcher may break confidentiality in order to safeguard patients, as risk of harm warrants a breach of confidentiality under the code of practice.

### **7.3 Potential Burden to patients**

The researcher conducting the research has experience interviewing vulnerable women and 20 years’ clinical experience caring for vulnerable patients and their families as a nurse and a midwife. These communication skills will be valuable as during the interviews it is possible that women or their relatives may discuss distressing events such as a stillbirth or resuscitation event. Should the participants become distressed they will be offered the chance to terminate the interview and be referred for appropriate follow up including being given contact details for additional support. This could be the bereavement midwife or other supportive groups such as the Patient Advice and Liaison Services and groups

such as APEC, SANDS or BLISS depending on the individual's situation. For staff interviews again sensitivity will be vital and referrals to staff support agencies may be made if they become distressed during the interview if they are recalling difficult clinical situations.

#### **7.4 Incentives**

Currently there are no incentives planned for this study.

#### **7.5 Ethics and R&D**

This study will be submitted for approval to an NHS Research Ethics Committee (REC) and other research governance procedures at the research site.

It will be conducted in compliance with the Research Governance Framework for Health and Social Care and Good Clinical Practice(GCP) (Department of Health 2005).

#### **8.0 Finances**

Funding is available for transcribing and interpreting services.

Estimated costs for transcription for 100hours of tape, which is 150 hours of typing (60 hours of interviews and 40 hours of ethnography) will be approximately  $150 \times £20 = £3,000$ .

Estimated costs for interpreting services for approximately 5 hours of language line will be approximately  $5 \times £22 = £112$ .

#### **9.0 Reporting and Dissemination**

A dissemination strategy will implemented from the start of the research so that communication made with consumer groups, patient participant groups, practitioners and policy makers are continued after the research is completed. The strategy is likely to expand during the three year process as more contacts are made.

The study will be written up for submission as a PhD thesis. A study report and summary will be prepared and findings will be prepared for abstracts, presentations, posters, for publication in peer reviewed journals, web publications. A lay report will be prepared in conjunctions with service users.

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## Appendix 8 REC letter



### Health Research Authority

NRES Committee London - Camberwell St Giles

Level 3, Block B

Whitefriars

Lewins Mead

Bristol

BS1 2NT

Telephone: 0117 342 1385

10 April 2015

Prof Jane Sandall

Division of Women's Health, Women's Health Academic Centre, King's Health Partners,  
10th Floor, North Wing St Thomas' Hospital, Westminster Bridge Road,  
London,  
SE 17EH

Dear Prof Sandall

<b>Study title:</b>	<b>Speaking Up, Listening and Responding; an exploration of factors affecting women speaking up about the safety of their health in maternity care</b>
<b>REC reference:</b>	<b>15/LO/0068</b>
<b>IRAS project ID:</b>	<b>159105</b>

Thank you for your letter of 18<sup>th</sup> March 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC at a meeting held on 10<sup>th</sup> April 2015. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Miss Tina Cavaliere, [nrescommittee.london-camberwellstgiles@nhs.net](mailto:nrescommittee.london-camberwellstgiles@nhs.net). Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).



## Ethical review of research sites

### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Non-NHS sites

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
IRAS Checklist XML [Checklist_22122014]		22 December 2014
IRAS Checklist XML [Checklist_29122014]		29 December 2014
IRAS Checklist XML [Checklist_18032015]		18 March 2015
IRAS Checklist XML [Checklist_19032015]		19 March 2015
IRAS Checklist XML [Checklist_30032015]		30 March 2015
Letters of invitation to participant	1	29 December 2014
Other [Nicola Mackintosh CV]		
Other [Debra Elizabeth CV]		
Other [Poster for Observation]	1	29 December 2014
Other [Response Letter to Committee]	1	18 March 2015
Other [Email invitation clean copy]	2	18 March 2015
Other [Email invitation tracked changes]	2	18 March 2015
Other [Interview maternity service users clean copy]	2	18 March 2015
Other [Interview maternity service users tracked changes]	2	18 March 2015
Other [Interview schedule for Patient and Public Involvement groups clean copy]	2	18 March 2015
Other [Interview schedule for Patient and Public Involvement groups tracked changes]	2	18 March 2015
Other [Interview schedule for staff clean copy]	2	18 March 2015
Other [Interview schedule for staff tracked changes]	2	18 March 2015
Other [Participant information sheet for interviews maternity service users clean copy]	2	18 March 2015
Other [Participant information sheet for interviews maternity service users tracked changes]	2	18 March 2015
Other [Participant Information sheet for patient and public involvement groups clean copy]	2	18 March 2015
Other [Participant information sheet for Patient and Public Involvement groups tracked changes]	2	18 March 2015
Other [Participant Consent form tracked changes]	V4	25 March 2015
Other [Participant Information sheet fro maternity service users. Tracked]	3	25 March 2015

Other [Participant Information sheet for interviews for health care workers tracked]	25.03.15	03 March 2015
Other [Participant Information sheet for interviews for Patient and Public Involvement Groups tracked changes]	3	25 March 2015
Other [Research Protocol. Tracked changes.]	3	25 March 2015
Other [Participant Consent form clean copy]	4	25 March 2015
Other [Participant information sheet for interviews maternity service users clean copy]	3	25 March 2015
Other [Participant Information sheet for interviews for health care workers clean copy]	3	25 March 2015
Other [Participation Information for interviews for Patient and Public Involvement Groups Clean]	3	25 March 2015
Other [Research Protocol Clean Copy]	3	25 March 2015
Participant information sheet (PIS) [Observation in the field information sheet for maternity service users ]	1	07 December 2014
Participant information sheet (PIS) [Observation in the field information sheet for health care workers]	1	07 December 2014
REC Application Form [REC_Form_22122014]		22 December 2014
Research protocol or project proposal [Speaking Up, Listening and Responding: an exploration of factors affecting women speaking up about the safety of their health in maternity care]	1	05 December 2014
Summary CV for Chief Investigator (CI) [Jane Sandall CV]	1	20 October 2014
Summary CV for student [Wendy Carter CV]	1	01 November 2014
Summary CV for supervisor (student research) [Prof Jane Sandall CV]	1	20 October 2014

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### User Feedback

NRES Committee London - Camberwell St Giles

Attendance at Sub-Committee of the REC meeting on 13 April 2015

Committee Members:

Name	Profession	Present	Notes
Ms Sally Gordon Boyd	Medical Ethicist	Yes	
Professor Mark Richardson	Paul Getty III Professor of Epilepsy; Head, Dept. of Clinical Neuroscience	Yes	
Dr Mark Tanner	Consultant Psychiatrist	Yes	

Also in attendance:

Name	Position (or reason for attending)
Miss Tina Cavaliere	REC Manager

## Append

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

15/LO/0068	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely

Pp Tina Cavaliere

Professor Mark Richardson  
Chair

Email: [nrescommittee.london-camberwellstgiles@nhs.net](mailto:nrescommittee.london-camberwellstgiles@nhs.net)

*Enc.* "After ethical review – guidance for researchers"

Copy to: Mr Keith Brennan  
Elizabeth Bruna, Guy's and St Thomas' NHS Foundation Trust

## **Appendix 9 Women and families information leaflet**

**Participant Information Sheet for Interviews for maternity service users V3  
25/03/15**

**Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning symptoms of preeclampsia speaking up about the safety of their health in maternity care**

### **Invitation to participate in the above study:**

We would like to invite you to take part in a research study. The study is exploring maternity service users raising safety concerns when they have early warning signs of preeclampsia in the antenatal, birth or postnatal period. This research is being undertaken as part of a PhD project by a King's College PhD student. The research is funded by the Health Foundation.

### **What is the purpose of this project?**

Currently there is little evidence that explores the possibility of how maternity service users can contribute to their own safety when they have a serious concern about their own health or the health of their babies regarding preeclampsia.

Specialist 'early warning systems' are used within maternity services to identify women who are unwell and need specialist treatment for deteriorating health. This research is going to explore whether women themselves can be an 'early warning system', are they informed enough to raise concerns at an early stage, do they feel comfortable to speak up and do health professionals address their worries in an appropriate way?

This research project will consist of 3 complementary elements; qualitative semi-structured interviews of representatives of public and patient involvement groups, women and their families and staff interviews.

By examining these factors we hope to be able to improve the management of preeclampsia by enabling maternity service users' to know when and how to speak up, and service providers' to listen and respond appropriately to users' concerns.

### **Has the study got ethics approval?**

The NRES Committee London - Camberwell St Giles has reviewed the study and given it ethical approval (15/LO/0068).

### **What will it involve?**

The researcher would like to hear your views about your journey through the maternity services. The researcher will ask questions about the types of concerns that are raised by maternity service users who have had preeclampsia or their relatives, and what factors influence their ability to speak up, be listened to and how to harness an appropriate response from health care providers. Your ideas regarding strategies to aid communication will also be of value.

### **Why have I been asked to take part?**

You may have experiences of the maternity services either as a service user, support partner or family member. Your experiences and opinions will help us understand how to improve the management of listening and responding to maternity service users when they raise concerns regarding preeclampsia symptoms in the antenatal, birth or postnatal period.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. It won't make any difference to the treatment you receive in any way whatever you choose to do.

### **What will participation involve?**

The researcher would like to invite you to do a confidential interview. It will cover topics as described above and will take approximately one hour. The time and place will be chosen for your convenience.

### **What if I want to withdraw?**

You may withdraw from the study at any time. You do not have to give a reason for withdrawing, and your care will not be affected.

**Are there any possible benefits?**

There will be no possible benefits for you regarding this research. We will give you feedback when the study is completed and feedback will be given to this hospital trust.

**Are there any possible risks?**

The interview will take an hour of your time.

If anyone's safety is at risk, this would be disclosed to the appropriate persons.

**Will my interview be confidential?**

All collected data will be confidential. A code name will be used instead of your real name to make sure everything you say is anonymous. No personal information about you will be held by the researcher. The interview recordings, transcripts and any related documents will be stored securely.

**What if I have any concerns?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact: Principle Investigator: Professor Jane Sandall: email: [jane.sandall@kcl.ac.uk](mailto:jane.sandall@kcl.ac.uk) Tel: 0207188 8149

If you have a complaint, you should talk to your research lead, Professor Jane Sandall, who will do her best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the xxxxxxxx

This trial is co-sponsored by King's College London and xxxxx. The sponsors will at all times maintain adequate insurance in relation to the study independently. Kings College London, through its own professional indemnity

(Clinical Trials) and no fault compensation and the Trust having a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

### **How and where will the results be published?**

The study will be written up for submission as a PhD thesis. A study report and summary will be prepared and findings will be prepared for abstracts, presentations, posters, for publication in peer reviewed journals, web publications. A lay report will be prepared in conjunctions with service users.

**Thank you very much for taking the time to read this leaflet.**

### **Contact details:**

#### **Researcher: Wendy Carter**

King's Improvement Science PhD Student

Division of Women's Health, Women's Health Academic Centre, King's Health Partners,

10th Floor, North Wing St Thomas' Hospital, Westminster Bridge Road, London, SE 17EH.

[Wendy.carter@kcl.ac.uk](mailto:Wendy.carter@kcl.ac.uk)

Tel: 07538358425

## **Appendix 10 Health Care Workers information leaflet**

### **Information Sheet for Interviews for Health Care Workers V3 25/03/15**

**Study Title: Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning symptoms of preeclampsia speaking up about the safety of their health in maternity care**

#### **Invitation to participate in the above study:**

We would like to invite you to take part in a research study. The study is exploring maternity service users raising safety concerns when they have an early warning sign or symptom of preeclampsia in the antenatal, birth or postnatal period. The study will be at xxxxxxxx between Feb 2015 and August 2015 This research is being undertaken as part of a PhD project by a King's College student. The research is funded by the Health Foundation.

#### **What is the purpose of this project?**

The aim of this study is to understand the factors that affect maternity service users' ability to raise early warning signs or symptoms of preeclampsia to health care providers and harness an appropriate response in order to facilitate optimal outcomes in the woman's and her infant's health. The study hopes to:-

- identify the range of signs and symptoms raised by women who have had preeclampsia, and their partners and families in pregnancy, birth or in the postnatal period.
- identify the contextual factors that influence women, their partners and families decision making when raising concerns regarding preeclampsia symptoms.
- To identify the organisational and social factors that influence the health care provider's ability to respond to concerns raised by maternity service users.
- To identify what strategies are in place that support women and their partners and families raising health complication concerns and providers responding to them.



This research project will consist of 3 complementary elements; qualitative semi-structured interviews with public and patient involvement group representatives, maternity service users and their families and staff.

By examining these factors we hope to be able to improve the management of listening and response to maternity service users when they raise signs and symptoms of preeclampsia.

### **Does the study have ethics approval?**

The NRES Committee London - Camberwell St Giles has reviewed the study and given it ethical approval (15/LO/0068).

### **What will it involve?**

The researcher would like to hear your views as a member of staff working in the maternity services about the types of symptoms regarding preeclampsia that are raised by maternity service users or their relatives. In addition the researcher is interested in the factors that influence the ability of maternity service users to speak up, and staff to be able to listen and give an appropriate response. Your ideas regarding strategies to aid communication will also be of value.

### **Why have I been asked to take part?**

You may have experiences of the maternity services as a health care worker. Your experiences and opinions will help us understand how to improve the management of listening and responding to maternity service users when they report symptoms of preeclampsia.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. It won't make any difference to the treatment you receive in any way whatever you choose to do.

### **What will participation involve?**

The researcher would like to invite you to do a confidential interview. It will cover topics as described above and will take approximately one hour. The time and place will be chosen for your convenience.

### **What if I want to withdraw?**

You may withdraw from the study at any time. You do not have to give a reason for withdrawing, and your care will not be affected.

**Are there any possible benefits?**

There will be no possible benefits for you regarding this research. We will give you feedback when the study is completed and feedback will be given to this hospital trust.

**Are there any possible risks?**

The interview will take an hour of your time and you may feel distressed talking about difficult clinical situations you have been involved in. If anyone's safety is at risk, this will be disclosed to the appropriate persons.

**Will my interview be confidential?**

All collected data will be confidential. A code name will be used instead of your real name to make sure everything you say is anonymous. No personal information about you will be held by the researcher. The interview recordings, transcripts and any related documents will be stored securely.

**What if I have any concerns?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact: Principle Investigator: Professor Jane Sandall: email: jane.sandall@kcl.ac.uk Tel: 0207188 8149

If you have a complaint, you should talk to your research lead, Professor Jane Sandall, who will do their best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the xxxxxxxxxxxxxxxxxxxxxxxx.

This trial is co-sponsored by King's College London and xxxx. The sponsors will at all times maintain adequate insurance in relation to the study independently. Kings College London, through its own professional indemnity (Clinical Trials) and no fault compensation and the Trust having a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient but

you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

### **How and where will the results be published?**

The study will be written up for submission as a PhD thesis. A study report and summary will be prepared and findings will be prepared for abstracts, presentations, posters, for publication in peer reviewed journals, web publications. A lay report will be prepared in conjunctions with service users.

Thank you very much for taking the time to read this leaflet.

### **Contact details**

#### **Researcher: Wendy Carter**

King's Improvement Science PhD Student

Division of Women's Health, Women's Health Academic Centre, King's Health Partners,

10th Floor, North Wing St Thomas' Hospital, Westminster Bridge Road, London, SE 17EH.

[Wendy.carter@kcl.ac.uk](mailto:Wendy.carter@kcl.ac.uk)

Tel: 07538358425

## **Appendix 11 Information Leaflet for PPI**

### **Participant Information Sheet for Interviews for Public and Patient Involvement Groups V3 25/03/15**

**Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning symptoms of preeclampsia speaking up about the safety of their health in maternity care**

#### **Invitation to participate in the above study:**

We would like to invite you to take part in a research study. The study is exploring maternity service users raising safety concerns when they have an early warning signs of preeclampsia in the antenatal, birth or postnatal period. This research is being undertaken as part of a PhD project by a King's College student. The research is funded by the Health Foundation.

#### **What is the purpose of this project?**

Currently there is little evidence that explores the possibility of how maternity service users can contribute to their own safety when they have a serious concern about their own health or the health of their babies regarding preeclampsia

Specialist 'early warning systems' are used within maternity services to identify women who are unwell and need specialist treatment for deteriorating health. This research is going to explore whether women themselves can be an 'early warning system' regarding their health or their babies health , are they informed enough to raise concerns at an early stage, do they feel comfortable to speak up and do health professionals address their worries in an appropriate way?

This research project will consist of 3 complementary elements; qualitative semi-structured interviews of representatives of public and patient involvement groups, women and their families and staff interviews.

By examining these factors we hope to be able to improve the management of preeclampsia by enabling maternity service users' to know when and how to speak up, and service providers to listen and respond appropriately to users' concerns.

#### **Has the study got ethics approval?**

The NRES Committee London - Camberwell St Giles has reviewed the study and given it ethical approval (15/LO/0068).

**What will it involve?**

The researcher would like to hear your views about the journey women and their families take through the maternity services. Questions will be about the types of concerns that are raised by maternity service users who have had preeclampsia or their relatives and what factors influence their ability to speak up, be listened to and how to harness an appropriate response from health care providers. Your ideas regarding strategies to aid communication will also be of value.

**Why have I been asked to take part?**

You are a representative of a public and patient involvement group. Your experiences and opinions will help us to understand how to improve the management of listening and responding to maternity service users when they raise concerns regarding preeclampsia symptoms in the antenatal, birth or postnatal period.

**Do I have to take part?**

It is up to you to decide whether or not to take part. It won't make any difference to the treatment you receive in any way whatever you choose to do.

**What will participation involve?**

The researcher would like to invite you to do a confidential interview. It will cover topics as described above and will take approximately one hour. The time and place will be chosen for your convenience.

**What if I want to withdraw?**

You may withdraw from the study at any time. You do not have to give a reason for withdrawing, and your care will not be affected.

**Are there any possible benefits?**

There will be no possible benefits for you regarding this research. We will give you feedback when the study is completed and feedback will be given to this hospital trust.

**Are there any possible risks?**

The interview will take an hour of your time. If anyone's safety is at risk, this would be disclosed to the appropriate persons.

**Will my interview be confidential?**

All collected data will be confidential. A code name will be used instead of your real name to make sure everything you say is anonymous. No personal information about you will be held by the researcher. The interview recordings, transcripts and any related documents will be stored securely.

**What if I have any concerns?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact: Principle Investigator: Professor Jane Sandall: email: [jane.sandall@kcl.ac.uk](mailto:jane.sandall@kcl.ac.uk) Tel: 0207188 8149

If you have a complaint, you should talk to your research lead, Professor Jane Sandall, who will do their best to answer your questions. If you remain unhappy, you may be able to make a formal complaint through the NHS complaints procedure. Details can be obtained through the xxxxxxx.

This trial is co-sponsored by King's College London and xxxxx. The sponsors will at all times maintain adequate insurance in relation to the study independently. Kings College London, through its own professional indemnity (Clinical Trials) and no fault compensation and the Trust having a duty of care to patients via NHS indemnity cover, in respect of any claims arising as a result of clinical negligence by its employees, brought by or on behalf of a study patient but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

**How and where will the results be published?**

The study will be written up for submission as a PhD thesis. A study report and summary will be prepared and findings will be prepared for abstracts, presentations, posters, for publication in peer reviewed journals, web publications. A lay report will be prepared in conjunctions with service users.

**Thank you very much for taking the time to read this leaflet.**

**Contact details:**

**Researcher: Wendy Carter**

King's Improvement Science PhD Student

Division of Women's Health, Women's Health Academic Centre, King's Health Partners,

10th Floor, North Wing St Thomas' Hospital, Westminster Bridge Road, London, SE 17EH.

[Wendy.carter@kcl.ac.uk](mailto:Wendy.carter@kcl.ac.uk)

Tel: 07538358425

## Appendix 12 Participant Consent form

### PARTICIPANT CONSENT FORM

**Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning symptoms of preeclampsia speaking up about the safety of their health in maternity care**

**Chief Investigator: Prof Jane Sandall**

**Researcher: Wendy Carter**

**Please initial box**

1. I confirm I have read and understood the information sheet (version 1 a: dated ###/###/2014) for the above study and have had the opportunity to ask questions.

☒

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my medical care or legal rights being affected.

☐

3. I am happy to be contacted by the researcher to make arrangements to discuss my knowledge and understanding of maternity services users' experiences of being listened to and responded to during their maternity journey.

☐

If yes, my contact no. is -----

4. I understand that I can withdraw permission to use the data within two weeks of the interview,

in which case the material will be deleted.

☐

5. I understand that my interview will be audio-taped and transcribed, but that no identifying information will be kept with the tape or transcription and that only members of the research team will listen to and read them.

☐

6. I understand that disguised and anonymised extracts from my interview may be quoted in the

write up of the study and in subsequent publications I agree to quotations from my interviews

being used in this way.

☐



7. I consent to information collected in the study being used in the event of my later losing capacity to consent.

☐

8. I consent to take part in this study.

☐

\_\_\_\_\_  
*Name of Participant*

\_\_\_\_\_  
*Date*

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Name of Person taking consent  
(if different from researcher)*

\_\_\_\_\_  
*Date*

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Researcher      Date*

\_\_\_\_\_  
\_\_\_\_\_

## Appendix 13 Dissemination

### Publications

Mackintosh, N., Sandall, J., Collison, C., Carter, W., Harris, J., (2018)  
Employing the arts for knowledge production and translation: Visualizing new possibilities for women speaking up about safety concerns in maternity. *Health Expectations; an international journal of public participation in health care and health policy*. DOI: 10.1111/hex.12660. Accepted for publication 1<sup>st</sup> December 2017.

Mackintosh, N., Rance, S., Carter, W. Sandall, J (2017) Working for patient safety: a qualitative study of women's help-seeking during acute perinatal events. 17 July 2017: *BMC Pregnancy and Childbirth* BMC 17: 232

Carter, W., Bick, D., Mackintosh, N. & Sandall, J.( 2017) A narrative synthesis of factors that affect women speaking up about early warning signs and symptoms of pre-eclampsia and responses of healthcare staff 13 Feb 2017 : *BMC Pregnancy and Childbirth*. 17, 1, p. 63

### Presentations and Posters

Mackintosh, N., Carter, W., Hrisos, S, O'Hara, J., Sutton, S., Ocloo, J., (2017) Workshop; *Creating enabling systems to facilitate patient and family contribution to safety*. HSRUK Symposium 2017, Nottingham Conference Centre, 6<sup>th</sup> July.

Carter W,, Bick D, Mackintosh N Sandall J (2017) "*Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning signs and symptoms of pre-eclampsia seeking help*", Poster presentation. 31st ICM Triennial Congress, Toronto 2017. 20<sup>th</sup> June.

Carter W,, Bick D, Mackintosh N Sandall J (2017) "Speaking Up, Listening and Responding; an exploration of factors affecting women with early warning signs and symptoms of pre-eclampsia seeking help", Oral presentation. NCT/KCL meeting 15th June.

Carter W, Bick D, Mackintosh N Sandall J (2017) "*Speaking Up, Listening and Responding: an exploration of factors affecting women with early warning signs and symptoms of pre-eclampsia participating in their own safety*". Presentation. QIRN 15th Quality Improvement Research Network Meeting, National Hospital of Denmark, Copenhagen. 1st/ 2nd May 2017

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